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ABSTRACT

As mandated by Illinois Public Act 84-1291, this report identifies the service needs of persons with autism, recommends service models, and offers a plan of action to ensure delivery of appropriate services within resources available. Three primary themes are emphasized: a need for intervention at the earliest point in time for persons with autism, a need for strong family involvement in training and implementing service plans, and a commitment to community integration and small residential settings in the community. The report begins by defining terminology and describing autism--its prevalence, characteristics, causal factors, and problems in diagnosis. "Treatment/Habilitation Models," describes medical approaches and psychological/educational methods for fostering normal development. Also described are specific training strategies for promotion of cognitive development, language development, socialization, and behavior changes and for reducing family stress. "Current Services for Persons with Autism" discusses residential programs, day programs, and case coordination services available in Illinois, offers a client profile, describes exemplary programs, and reviews characteristics common to exemplary programs. "Service Needs for Autism" identifies the need for family programs, diagnostic assessment, educational/vocational/employment programs, residential programs, public education, and professional/paraprofessional training. The report concludes with a list of recommendations. A separately published 13-page "Executive Summary" is appended. (JDD)

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JANUARY 1987

A REPORT ON THE SERVICE NEEDS OF PERSONS WITH AUTISM

REPORT TO THE ILLINOIS GENERAL ASSEMBLY IN RESPONSE TO PUBLIC ACT 84-1291

Illinois Department of Mental Health and Developmental Disabilities

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A REPORT ON THE SERVICE NEEDS OF

PERSONS WITH AUTISM

In Response to P.A. 84-1291

Prepared by the Department of Mental Health
and Developmental Disabilities

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STATE OF ILLINOIS
DEPARTMENT OF MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES

CENTRAL OFFICE
401 South Spring Street
Springfield, Illinois 62706

January 13, 1987

To The Honorable Members of the General Assembly

I am pleased to submit for your review and consideration the report mandated by Public Act 84-1291 entitled "A Report on the Service Needs of Persons With Autism". This report was prepared in response to legislation introduced and passed by Representative Stephens and Senator D'Arco and signed by Governor James Thompson. By highlighting their needs, recommending models and suggesting plans of action, I hope and trust this report will strengthen the services system for autistic persons.

The Department is pleased to have had an opportunity to work with both the Legislators and concerned Illinois citizens throughout the legislative process and during the writing of this report. Because of their hard work and dedication, this report represents a sound document guiding the Department's current and continued commitment to serving the autistic population.

I look forward to and encourage your continued interest in our efforts.

Respectfully submitted,

Ann Kiley

Ann Kiley
Director

PREFACE

Public Act 84-1291 emanated from the work of a group of informed and concerned parents of children and adults with autism to improve the service options and life choices available to these individuals. House Bill 2816, sponsored by State Representative Ron Stephens and State Senator John D'Arco, was introduced in the 1986 spring session of the General Assembly and signed into law by Governor James Thompson on August 19, 1986.

The major directive of PA 84-1291 is to identify the service needs of persons with autism, recommend service models, and prepare a plan of action to ensure this population is appropriately served within the resources available to the Department.

In preparing this report, the Department of Mental Health and Developmental Disabilities solicited input from individuals within the state who were parents or professionals active in the field of autism. Research material prepared by academics and consultants as well as other state reports and model programs were also consulted for the drafting of an Illinois plan. Special recognition needs to be given to Carol Brown, the Department staff person who coordinated the preparation of the plan, Tamar Heller and Joyce Falck-Bertram of the Illinois Institute for Developmental Disabilities, who compiled research materials on exemplary practices and characteristics of autism, and Marie Havens, who assisted in the editing of the final report.

Finally, it should be pointed out that due to the diversity of opinion regarding treatment approaches for autism, this report is not reflective of a consensus opinion of all interested individuals. The report does, however, attempt to present a balanced view of these differing opinions. Three primary themes are emphasized: a need for intervention at the earliest point in time for persons with autism, a need for strong family involvement in training and carrying out service plans and a commitment to community integration and the availability of small residential settings in the community. This report is our first step in addressing these concerns.

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INTRODUCTION

The purpose of the report contained herein is to review the service needs of persons with autism, to explore service models, and to detail a plan of action to address appropriate services for this population.

This report responds to the requirements of Public Act 84-1291 (H.B. 2816), which requires the submission of a report to the General Assembly by January 1, 1987.

Definition

For purposes of this report, the Department of Mental Health and Developmental Disabilities will adopt both the definitions contained in the Mental Health and Developmental Disabilities Code as well as the more descriptive definition of P.A. 84-1291.

Specifically, the Mental Health and Developmental Disabilities Code defines developmental disabilities as:

> .. disability which is attributable to: (a) mental retardation, cerebral palsy, epilepsy, or autism; or to (b) any other condition which results in impairment similar to that caused by mental retardation and which requires services similar to those required by mentally retarded persons. Such disability must originate before the age of 18 years, be expected to continue indefinitely, and constitute a substantial handicap. (Chapter 91 ½, Section 1-106).

P.A. 84-1291 affirms that autism is a severely incapacitating lifelong developmental disability and further describes:

a. May be manifested before a person is 30 months of age.

b. May be caused by physical disorders of the brain, and;

c. Is characterized by uneven intellectual development and a combination of disturbances in the rates and sequences of cognitive, affective, psychomotor, language, and speech development. This syndrome is further evidenced by abnormal response to sensory stimuli, problems in developing social relationships, and ritualistic and compulsive behavior. (Chapter 91 ½, Section 100-56).

Consistent with the above definitions, the National Society for Children and Adults with Autism (NSAC) defines autism as:

> .. a disability that severely impairs the way sensory input is processed, causing problems in communication, social behavior and in learning. It typically appears during the first thirty months of life. Symptoms of autism occur in approximately 15 out of every 10,000 births, and are four times more common in males than females. It has been found throughout

the world in families of all racial, ethnic, and social backgrounds. No factors in the psychological environment of a child have been shown to cause autism. There is strong evidence of neurological and biochemical implications. (NSAC, Autism Fact Sheet, No. 83-1877). A more detailed behavioral definition of the syndrome of autism is contained in Appendix i.

Autism is thus established as a severe disability which originates early in life and can be expected to continue indefinitely. It is important to understand, however, that the characteristics of autism may vary significantly among persons with autism, depending upon the degree of cognitive, behavior, and communication disorder and the manner in which these disorders are manifested. It should also be emphasized that many in the field believe that autism is first and foremost a communications disorder which dictates the type and approach to service delivery. The recognition of these variations in the severity of the disorder is most important to understand the variety of treatment types and service needs.

Prevalence

Autism is considered a low incidence disability, being the fourth most common developmental disability behind mental retardation, epilepsy, and cerebral palsy. The low number of individuals with autism does not, however, negate the need to develop a responsive service system. The problems facing families of relatives with autism are unique and sometimes overwhelming.

Estimates vary as to the number of individuals with autism residing in Illinois. The difference in estimates is mainly due to the methodologies used or the scope of the definition of autism. For example, some estimates may include individuals who are higher functioning but may exhibit autistic like behaviors. Others may include in the prevalence number only those individuals with a primary diagnosis of autism. Finally, some figures refer to incidence of autism at birth, while others count individuals diagnosed as autistic at any one point in time. For these reasons, it is not unusual to have different published figures as to how many autistic individuals reside in a state or in the nation.

A review was conducted of prevalence figures for autism which have been developed for Illinois. These figures were compared to generally accepted national statistics. From these data, an estimate of the number of persons in the state was derived which assumed persons with a diagnosis of autism and does not include the larger number of individuals with "autistic like" behavior.

Prevalence figures prepared by the Illinois Institute for Developmental Disabilities (IIDD) in 1985 indicate that 3,885 Illinois residents are autistic. This estimate was based upon both a review of data in the Illinois Client Information System (ICIS) and a study conducted by the University of Minnesota. The use of ICIS data involves a "rates in treatment" approach which means examining existing data to estimate the affected population. This

may underestimate the actual prevalence, as individuals not currently in the service system are not considered. The use of the University of Minnesota estimates tended to offset the undercount problem. Appendix ii contains more detail on the prevalence estimates developed by IIDD.

A second prevalence estimate is provided by The Illinois Autism Study, a project undertaken through funds from the Governor's Planning Council on Developmental Disabilities and conducted by the Illinois State Board of Education. This study emphasized the difficulty of properly identifying the number of individuals with autism in Illinois due to the lack of public and professional awareness of the characteristics of the syndrome and exclusion of the disability from the computerized data base. Although this study was published in 1977, these problems in properly identifying autism continue today. Recognizing the problems of counting actual autistic persons, this study instead drew upon expert studies to apply to Illinois. Studies conducted by Lotter and Brask yielded an estimate of 4.5 autistic persons per 10,000. Applied to Illinois, this rate would indicate approximately 5,000 individuals with autism statewide. Dr. Lorna Wing alternatively included autistic like behavior in the definition and concluded a prevalence rate of 20.1 per 10,000. This would yield 22,832 individuals with autism in Illinois.

In a proposal submitted to the Governor's Planning Council on Developmental Disabilities (GPCDD) in 1981, Arrise, Inc. estimated a prevalence rate of 5 per 10,000, based upon generally accepted national statistics. Again this yields an estimate of close to 6,000 autistic individuals in Illinois.

Finally, NSAC estimates autism occurs in 15 out of 10,000 births. Since this applies to incidence at birth rather than prevalence at a point in time, this figure is not directly comparable to the others and would yield a lower estimate.

Although consensus is not possible because the estimates vary depending upon the assumptions used, the DMHDD concluded that an estimated rate of 5 per 10,000, or approximately 6,000 individuals with autism, represents a primary need population in Illinois.

Research Method

In determining the problems facing families of persons with autism in Illinois, the Department undertook a study which involved a review of historical considerations, current services in Illinois, exemplary programs in other states, and national trends in services for autistic persons. Through the resources of the Illinois Institute for Developmental Disabilities, the Department made use of national experts and more recent research in the field of autism.

In identifying model programs, the National Society for Children and Adults with Autism (NSAC) was contacted as well as state NSAC chapters in Michigan and New Jersey and Mental Health officials in several states. The Illinois Society for Autistic Children (ISAC) was most helpful in identifying resources within Illinois. The Department also reviewed past efforts in the financing

of services to the autistic population. The latter part of this report thus presents recommendations which emanate from this review of literature, research and model programs.

An important component in formulating recommendations is the input received from parent and provider groups on the most pressing needs now facing families who have autistic relatives. A method of soliciting input was formalized by the selection of "key informants" for comment. These key informants are considered experts in dealing with autism. Most of the key informants are parents of autistic children and adults and have thus personally experienced the frustrations of seeking appropriate care for this special needs population. Key informants were also selected based upon their geographic location. e.g., urban versus rural, and the ages of their children who would present varying service needs. Based upon comments received on a preliminary draft, many sections were revised and additional expert opinion was added.

A listing of key informants and other knowledgeable individuals used for consultation is contained in Appendix iii.

As a final comment, it should be noted that much diversity of opinion was received by the Department. In many cases this made it difficult if not impossible to present a "consensus" position on factors such as behavioral strategies and implementation issues. As such, the Department has attempted to present a balanced view of the diverse positions.

PART ONE
DESCRIPTION OF AUTISM

Characteristics of the Syndrome

Autistic children and adults typically have multiple handicaps in their communication, behavior and social abilities. Language problems are often associated with impairments in sensorimotor, visual, and auditory perception. Health and medical problems are also common as many persons with autism acquire seizure disorders during adolescence which continue for life. A Delaware report summarized the most common characteristics of autism; these may vary in severity with each individual affected by autism:

- Severe impairment of speech or lack of speech--
  - echolalia, jargon, and word order confusion.
  - poor volume control and inappropriate inflection.
  - inability to understand and/or process verbal or nonverbal communication.
  - pronomial reversals.
  - rote-like, memorized phrases and expressions.
- Impairment or complete lack of appropriate relatedness or interaction with single children, parents, adults, and objects--
  - avoidance of eye contact.
  - abnormal degree of detachment or non-affection.
  - abnormal degree of attachment to objects.
  - grossly inappropriate behavior reactions (e.g., tantrums, inappropriate laughter).
- Extreme distress due to minor non-discernible changes in the environment (structure or time).
- Lack of intellectual development or retardation in language and cognition, although sometimes accompanied by normal or superior abilities in other areas.
- Repetitive, peculiar, and inappropriate use of toys and objects--
  - bizarre mannerisms.
  - self-stimulation (e.g., hand flicking, humming).
  - repetitive body motions (e.g., rocking, spinning).
  - ritualisms and/or repetitive behavior.
- Unusual reactions to perceptual stimuli, such as seeming not to hear certain sounds and over-reacting to others, holding hands over ears, "looking through" objects, and poor eye contact.
- Inability to perform certain gross and/or fine motor activities (e.g., walking with a peculiar gait, limpness in fingers, inability to hold a pencil appropriately).

- Onset of disorders at birth or apparently normal early development followed by failure to maintain normal functioning, especially in critical cognitive and communicative areas.

- Tendency to fixate on the extreme polarities of behavior--

  - hyperactivity or passivity.
  - apparent insensitivity to pain or hypersensitivity to tactile stimulation.

- Self-injurious, destructive and aggressive behavior.

("State of Delaware General Guidelines for the Development of Programs of Special Education and Related Services for Children and Youth with Autism").

Causal Factors in Autism

During the four decades that have passed since Kanner (1943) delineated the syndrome of infantile autism there have been important advances in our understanding of the nature of the condition.

First, studies have made it clear that autistic children and adults suffer from a basic cognitive deficit and that this deficit underlays many other language and behavior problems (Rutter, 1983). On IQ testing approximately 60% have scores below 50, 20% between 50-70 and only 20% greater than 70. Autistic children are distinguished by their pattern of better non-verbal than verbal skills and often by distinct splinter skills in music, mathematics, or in using spatial concepts, even though they may be severely retarded in other areas.

Second, in many cases overt organic brain dysfunction is present as described below:

- About a quarter of autistic children develop epileptic seizures during adolescence. Seizures are especially prevalent among autistic individuals with moderate to profound levels of mental retardation. (Rutter, 1970) Some estimates of the incidence of seizures go as high as 60% for the more severely retarded autistic individuals.

- Biochemical studies suggest elevated/deficient levels of neurotransmitters and inhibitors (e.g., serotonin).

- Initial findings of computerized tomography (CT) brain studies suggest that in autism both sides of the brain may be affected, with the left side probably more severely affected than the right. A wide variety of brain abnormalities have been reported including ventricular enlargement, a reversed pattern of asymmetry, temporal horn abnormalities, and various localizable abnormalities. The cause of these abnormalities could stem from a variety of central nervous system diseases (DeMyer, 1982).

- Studies have shown a sporadic association of autism with various diseases such as congenital rubella or infantile spasms and with perinatal complications (Rutter, 1985).

- Both twin and sibling studies have additionally pointed to the possible importance of genetic factors (DeMyer, 1982). The prevalence of autism in siblings is about 50 times that of the general population. Twin and sibling studies also suggest that it is the language or cognition component that is inherited rather than the full syndrome of autism.

It is important to emphasize that there are no data to support the previously held belief that emotionally cold parents are responsible for autism. In addition, parents of autistic children do not as a group have extreme personality types or a rate of mental illness higher than the general population.

Problems in Diagnosis

Many parents of autistic children believe a weakness in the service system is the failure to properly identify the symptoms of autism. This lack of recognition of autism can have serious ramifications for the affected individuals as well as the families. Parents are usually the first to be aware of maladaptive emotional and social behaviors in their infant or young child. However, few parents are aware of the symptoms of autism prior to being informed of this disorder by a professional. Even some professionals fail to recognize autism when they see it. Without accurate diagnosis of autism, inappropriate services may be provided or intervention may not occur at the earliest time. In essence, if the problem is not identified accurately, it cannot be treated. It is, therefore, essential that the description and characteristics of autism as defined herein be available to diagnosticians as well as staff in Illinois health and education fields. A program of community and professional education is essential.

The work of Dr. Mary Coleman on the biological causes of autism also needs to be considered in the development of diagnostic procedures. Consideration of the biological causes of autism offers new opportunities for addressing associated problems through medical intervention. Dr. Coleman notes that early isolation of biological causes of autism increases the effectiveness of subsequent treatments.

It is important that diagnostic evaluations include multiple disciplines as autism entails multiple handicaps. Proper programming depends on consistency and coordination of services from each discipline. A prerequisite is that diagnostic evaluations are communicated to all people providing services to the autistic individual.

PART TWO
TREATMENT/HABILITATION MODELS FOR AUTISM

Treatment/Habilitation Models

The major goal of treatment for autism must be to provide skills for independent functioning in community settings by fostering normal development, including cognitive, language, and social development. Further goals include: replacing the negative behavior characteristics (e.g., rigidity/stereotypes, destructive, self-abusive) with appropriate social behaviors, and alleviation of family distress.

The findings about each of the possible causal factors have led to very different therapeutic orientations. Focus on medical causes has led to medical treatment, while focus on cognitive or emotional deficits has led to psychological/educational intervention methods. There are no treatment programs which are effective for all persons with the disability; various treatment technologies are also very divergent in approach.

Medical Approaches

Drug treatments, such as non-sedating antipsychotics, tricyclic antidepressants, and anti-convulsants have had only modest success although they are useful in the treatment of temper outbursts, sleep disturbances, aggression, and seizures. Megavitamin therapy and reduction of serotonin levels have resulted in some short-lived gains for small samples of autistic children (Rutter, 1985). The restriction of diets to natural and pure foods which eliminate additives or artificial coloring, such as the diet espoused by Dr. Feingold, have also been found to result in improved behavior and reduction of hyperactivity in some cases. The fields of psychopharmacology and nutrition need further exploration and development. Dr. Bennett Leventhal of the University of Chicago advocates a "marriage" between medical treatment and a strong behavior programming strategy, noting that it is important that professionals from each discipline work together.

Psychological and Educational Methods

Psychological and educational methods have shown more promise than the medical approaches in improving the functional adaptation of autistic individuals in the areas of skill development, language usage, social interaction, and behavioral control. Before the 1970s, treatment was nearly always psychodynamically oriented and involved individual therapy with the child and mother, who was held largely responsible for the child's condition. Also, residential therapy that allowed the child to receive psychotherapy and that took him/her away from the home influence was advocated. There was no support for the mothers; in fact, children were often totally separated from them. The results were disappointing, with little improvement in the autistic child's social, speech, and cognitive functioning. Currently, the main psychological/educational approaches entail systematic and intrusive programming based on behavior management techniques. Since the early work by Ferster and DeMyer (1961) many studies have demonstrated that while behavioral

techniques are not a cure for autism, they lead to more significant increases in functioning than when the autistic individual is educated with permissive and unstructured methods.

General Considerations in Enhancing Overall Learning

There are specific considerations in promotion of learning by autistic individuals. Because they lack sufficient self-direction and have difficulty in screening out tactile and visual stimuli, there is a need to structure the learning situation, providing guidance and supervision throughout task performance. It is helpful to program the learning through sequencing elements, providing prompts for long periods, and shaping behaviors to encourage them to work independently.

Many autistic individuals exhibit over-selectivity in their response to cues - focusing on one to the neglect of others (Lovaas, Koegel, & Schreibman, 1979). Consequently, learning tends to be enhanced if they are given more cues or prompts than needed (Schreibman, 1975). For example, a person with autism might continue to write with a pen even though it had run out of ink, unless taught that the ink is the cue rather than the pen's motion.

Autistic individuals' tendency not to generalize their learning to settings outside the classroom points to the importance of aiming therapeutic interventions at their natural environments, working with parents at home and ensuring close links between programs at home and school (Hemsley et al, 1978). To increase community integration, the entire community must be used as the laboratory for learning. In addition, generalization of learning can be increased by the following steps:

- training in multiple settings;
- ensuring that cues, stimuli, and rewards are comparable across settings;
- use of intermittent rather than continuous reinforcement;
- emphasis on the development of self direction, self monitoring, and use of skills.

Autistic individuals tend to respond adversely to failure by displaying problem behaviors and by retreating to a stereotyped response style (Koegel & Egel, 1979). Hence, it is necessary to organize the learning tasks into small steps that result in minimal errors and maximal success.

Specific Training Strategies

Promotion of cognitive development. Because autistic individuals tend to isolate themselves, they often lack the learning experiences that stem from adult-child interaction. Thus, it is necessary to plan structured periods of interaction. Defects in comprehension indicate a need for individual instruction (at least at initial task assignments) and communication in short, easily understood sentences. Especially with younger and more handicapped autistic children, the learning situation and the teaching itself need to be more structured than for normal children (Schopler et al, 1971). Since autistic individuals tend to learn by rote

without attention to meaning, it is necessary throughout all teaching to focus on comprehension. To ensure that they have success experiences and that they profit from their learning experiences, teaching needs to be provided at an appropriate developmental level.

Promotion of language development. In language development the primary need is not to give the autistic individual "words" but to provide a total functional communication system that will facilitate social communication. In the long term, training has a greater effect on language usage than on basic language capacities (Howlin, 1980). Despite the many positive results of attempts to teach speech to persons with autism, some 50% of this population is likely to remain functionally mute (Rutter, 1982). If there is minimal progress with speech in spite of the presence of language comprehension, sign language may be worthwhile (Carr, 1979). The use of signs may actually enhance spoken language. On the other hand, it has been noted that signing has limitations for this population because of its temporal qualities and its limited usefulness in heterogeneous community settings (Schuler & Baldwin, 1981). Other systems which have augmented communication include written words, pictorial systems, and computer technology (Yoder & Calculator, 1981; Prizant, 1982). The emphasis should be on developing a functional communication system which works for the specific individual.

Promotion of socialization. The lack of social initiative and responsiveness to others among autistic individuals necessitates structuring their interactions so that they are reciprocal and social rather than solitary. This entails deliberate intrusion into their activities in a pleasurable way. Direct teaching of social skills by adults may also lead to social improvement. Integration of autistic individuals with non-autistic individuals is often not useful in promoting socialization since the autistic individuals' unresponsiveness discourages others from interacting with them. When such integration has been successful, it occurs in very carefully structured environments, where the educational programming is geared to promote interactions. However, some studies have shown that non-autistic peers can be encouraged to play with autistic children, resulting in social gains (Lord, 1984). Institutionalized care entailing multiple caregivers and often inconsistent caretaking is contraindicated, especially for young children.

Behavior changes. Various behavioral techniques have been used to reduce the rigidity and stereotypes common to autism. One is "graded change" in which changes in patterns and routines are introduced in small steps. Another approach is to change the environmental features which are likely to elicit these behaviors, such as barren, unstimulating environments (Baumeister, 1978). The introduction of alternative incompatible behaviors will also reduce stereotypes.

Operant techniques are most often used to control maladaptive behavior, which includes aggressive, self-injurious or destructive behaviors. This entails breaking tasks into small steps, providing feedback, teaching alternative responses and using positive reinforcement. The aim in

providing reinforcements is to move from material rewards to social reward. Eventually, the objective is to develop internal self-directed control so that appropriate behaviors are self-reinforcing and not just determined by external rewards. Another technique which has been useful in promoting behavioral changes is the gentle teaching approach (McGee, Menousek and Hobbs, 1986). Bonding is the first goal of gentle teaching - moving the person away from aggressive self-injurious, avoidant, or self-stimulatory behavior and toward relationships at first with direct caregivers and eventually with the community at large. The main assumption of this approach is that it is possible and necessary to teach bonding by transmitting the value inherent in both human presence and social interaction.

The use of aversive techniques in the treatment of severe behavioral disturbance is a growing controversy. Aversive techniques have been typically used to control behaviors that pose real and imminent danger to either the individual displaying the behavior pattern or others with whom the individual has contact. Aversive programs seek to reduce the rate and intensity of the dangerous behavior either by delivering a punishing event (e.g., shock, noxious stimulus) contingent upon occurrence of the behavior or by withdrawing positive reinforcement (e.g., time-out). Early studies by Lovaas and Simmons (1969) used electric shock to control self-injurious behaviors. There is now a general consensus that the use of punishment is to be considered only after positive reinforcement-based procedures have been used without success. The controversy centers around whether aversive techniques (particularly those involving physical punishment) have any role in programming for autistic children. Matson and DiLorenzo's (1984) review of punishment strategies stresses their usefulness for individual cases in overcoming severe behavior problems such as dangerous self-injurious behavior. On the other hand, other researchers (LaVigna & Donnellan, 1986) have argued that aversive procedures are not only unnecessary but are less likely to produce long-lasting changes in behavior than are reinforcement-based alternatives.

Reducing family distress

Families face many emotional as well as practical burdens in caring for autistic individuals who tend to be unresponsive, difficult to play and talk with, and demanding in their needs for supervision and structure on a full-time basis. Families need a full understanding of the autistic person's condition and of learning principles to follow in handling their behavior. This entails comprehensive feedback on diagnostic assessment and the development of coping skills to deal with the autistic individual on a daily basis. Parent training programs that emphasize behavior management are beneficial to families. Relying on family members as co-therapists in training the autistic individual raises some concerns, as it may have adverse effects on other family members. Hence, the degree of family involvement must be determined by each family's unique situation and characteristics. Counseling and case management can help parents deal with emotional issues related to having and rearing an autistic child.

Most importantly, families can benefit from support services such as in-home and out-of-home respite, self-help advocacy groups, financial provisions, transportation services, dental care, out-of-home residential options, and suitable educational and vocational/employment programs.

PART THREE
CURRENT SERVICES FOR PERSONS WITH AUTISM

Availability of Services

In addition to state facility care, the Department of Mental Health and Developmental Disabilities provides a wide variety of residential day program and community support services for persons with developmental disabilities, including persons with autism. (See Appendix iv).

Ideally, these services should be available to any person with developmental disabilities, including autism. In reality, many programs are not structured or staffed to deal with behavior problems or communication needs. Since autism is to a great degree a communications disorder, programming must be structured to deal with the communicative nature of autism. The failure to develop a functional communication system for autistic clients or the inability of staff to deal effectively with behavior problems often leads to the exclusion of autistic clients from services that are generally available to other persons with disabilities. It is the consensus of providers, parents, and advocacy organizations within the state that the service system for developmental disabilities does not provide sufficient access for autistic persons.

As an outgrowth of the limits in the service system for developmental disabilities, several agencies or programs have been developed in Illinois which target their services specifically to persons with autism. Four agencies currently provide services exclusively to autistic clients. A fifth agency is anticipated to begin providing funded services in FY 1987. Their services range from case coordination to day programs and residential care. A brief synopsis of each agency is included below.

Arrise

DMHDD FY 1987 Funding

	$	Clients
Child Group Home	$ 193,422	6
Vocational Development	$ 175,870	17
Supported Employment	$ 114,087	12
Administration	$ 55,079	N/A
Habilitation	$ 93,012	6
TOTAL	**$ 631,470**	

Arrise, based in Forest Park, serves persons with autism and other autistic like developmental disabilities. Its primary goal is to promote the well-being of autistic children and adults and their families. The agency links programs and services to the needs of persons with autism, provides family assistance in dealing with the disability, promotes research in the area of autism, and promotes public awareness of autism.

Arrise has worked closely with programs affiliated with NSAC in developing services. In particular, Arrise has worked with the Jay Nolan Center in California, a program which successfully operates residential programs for persons with autism.

Arrise opened its first group home in 1980 in Forest Park. This home serves six children or young adults with ages ranging from seven to eighteen years. Arrise also operates an intermediate care facility for fifteen or fewer individuals, the first of its kind in the Chicago area. Six autistic adults currently reside in the ICFDD fifteen which is located in Oak Park. Additional habilitation support is provided to the agency for special behavior programming to address the needs of some residents.

Arrise operates additionally a vocational development program for 17 autistic individuals and a supported employment program funded this past year for 12 clients. This emphasis on vocational developmental enhances the potential for individuals with autism to live more self sufficient and meaningful lives.

Blare House

DMHDD FY 1987 Funding

	$	Clients
Administration	$ 32,589	N/A
Habilitation	$216,813	8
Adult Group Home	$172,687	8
TOTAL	**$422,089**	

Blare House, located in Morton Grove, has focused on the development of residential alternatives for individuals with autism. With start up support from DMHDD, the agency has opened two 4-bed group homes for adults since May, 1984. These homes are licensed as Community Residential Alternatives, but receive additional habilitation supplements for special behavior programming to address the needs of some residents. Residents of the group homes attend day programs operated by a consortium of Blare House, Arrise and Rimland School.

Blare House has received a grant from the Governor's Planning Council on Developmental Disabilities and construction funding from HUD for a third adult group home.

Illinois Center on Autism

DMHDD FY 1987 funding

	$	Clients
Case Coordination	$ 46,707	37
Developmental Training/Child	$ 55,243*	41
Developmental Training/Adult	$ 18,160	2
Family Support	$ 70,712	37
TOTAL	**$190,822**	

* The State Board of Education also funds the Children's Developmental Training program.

The Illinois Center on Autism is a nonprofit community-based agency established in Fairview Heights in 1978. The Center provides services for autistic children through adulthood and is widely regarded as an excellent resource center in Illinois. The agency's goal is to offer alternatives to institutional placement by providing a continuum of day services, case coordination and family support. The Center provides psychological, behavioral, and speech evaluations prior to admission. The day programs for children are offered in two sites, one in Fairview Heights and one in Swansea. These programs include both developmental training and a full range of educational services. The Center recently initiated a limited adult day program for persons transitioning from public school or children's developmental training.

The Center utilizes the Premach principle of teaching, in which 15 minute segments of disliked activity are followed by 15 minutes of liked activity. This program has been effective in serving autistic clients who function at the severe/profound level and who exhibit varying degrees of behavior problems.

The agency also provides in-home training to parents to facilitate the implementation of behavior modification techniques and spoken and sign language acquisition, and provides a variety of other family support services. Finally, the Center offers case coordination services to individuals with autism throughout southern Illinois.

Resources for Retarded and Autistic Families (RRAF)

This organization was incorporated in 1981 as a nonprofit service provider in Hinsdale. Prior to that time, the organization was part of United Services for the Autistic. RRAF's mission is to serve individuals with autism who have been rejected by other service agencies through individually tailored day programs and eventually residential programs.

The agency currently operates a volunteer service providing a therapeutic recreational program on Sundays for eight adult clients with autism. RRAF also provides overnight and day trips for young adults and children. RRAF is now proposing the initiation of an adult developmental training program for eight persons who reside at home. It is anticipated that this program will be funded in fiscal year 1987.

Rimland School for Autistic Children

DMHDD FY 1987 Funding

	$	Clients
Developmental Training/Child	$ 77,099*	18
Developmental Training/Adults	$ 90,001	7
Leisure Time	$ 3,941	9
Habilitation	$ 79,215	6
Adult Group Homes	$125,462	6
TOTAL	**$375,718**	

* The State Board of Education also funds the Children's Developmental Training program.

Rimland School in Chicago provides services to developmentally disabled individuals who are diagnosed as autistic or having autistic like behaviors. Rimland was started in 1971 in response to the needs of children who have been excluded from public school programs because of the severity of their communications and behavior disorders.

Rimland school currently operates three educational programs for children. The agency also offers developmental training for autistic adults. The teaching approach is multi-sensory and utilizes techniques from social learning theory, operant conditioning, and reinforcement therapy.

In addition to day programs, Rimland also operates a weekend respite program between October and June, a summer residential camp, and two group homes for autistic adults located in Glenview and Highland Park.

Other Programs for Persons with Autism

In addition to the above agencies which focus exclusively on autism, some agencies provide a component of their overall programs to persons with autism. Some examples of these programs are:

Child Development Center

The Child Development Center, part of the Dysfunctioning Child Center at Michael Reese Hospital in Chicago, provides a day program for severely

handicapped children, most of whom are non-verbal and autistic or have autistic like behaviors. This program serves the Chicago area and receives funding from the State Board of Education. The Center integrates clinical services with teaching and employs a multidisciplinary approach. Staff includes teachers, speech and occupational therapists, psychologists and nurses. Program capacity is for 48 children ages 3-12, with emphasis on the younger age group. Dr. Margaret Creedon was formerly director of this program and now provides consultation in curriculum development.

Illinois Society for Autistic Children

ISAC is a state chapter chartered in 1976 of the National Society for Children and Adults with Autism. These organizations are comprised of parents and families of persons with autism as well as professionals in the field. The Board of Directors is comprised of volunteer members representing parents and professionals; these directors also represent six local chapters in the state. Local chapters provide information and family support as well as organizing meetings and fund raising. An information and referral network is operational at state and local chapters. The group is dedicated to the education and welfare of children and adults with severe disorders of communication and behavior. The state chapter sponsors advocacy and parent training workshops, publishes a quarterly newsletter on issues of importance to autism, and holds annual conferences to present and share the latest techniques and research in the field of autism. ISAC recently initiated a sibling training and support program in the Chicago area which will eventually be expanded statewide. In addition, ISAC plays an active role in lobbying for legislative changes and was key to the enactment of P.A. 84-1291.

Little Friends Group Home: This six bed group home, opened in 1981, provides an intensive five day residential program for autistic children age 6-13 years. Children remain in the group home from Sunday night through Friday and return to the parents' home on weekends. Parents also receive training in dealing with their children's behavior problems from the group home staff. The duration of the program is two years for each resident. A key component of the program is the integration of group home and natural home in the acquisition of daily living skills. At the end of the two-year training period, children are to return full-time to the natural home. Staff receive training twice a year from a behavior consultant to facilitate addressing the needs of autistic children.

Ray Graham After School Programs: This program has been operational in DuPage County since 1977 and was initially started through a grant from the GPCDD. The program provides after school care for nine autistic children and young adults age 6-18 years as well as a Saturday program for ten autistic persons of all ages. Staff receive training twice a year and the programs maintain a one to one ratio. Ray Graham has recently initiated a weekday afternoon adult program currently serving three autistic clients and projected to serve twelve adults when fully operational.

Appendix v lists additional agencies and state facilities which reported serving autistic clients, based on an October, 1986 report of the Illinois Client Information Systems (ICIS) data file. Appendix vi contains a listing of community agencies providing respite services in FY 1987. However, these respite providers do not necessarily serve individuals with autism.

Five Year Expenditure Overview

The Department cannot track funding commitments specifically for autistic individuals served by the Department since data entry forms for grants and purchase care programs do not require the identification of autism. Instead, an analysis of DMHDD funding of the four agencies exclusively serving an autistic population are arrayed below. This does not include funding by the Illinois State Board of Education (ISBE) for children with autism. The state fiscal year runs from July 1 to June 30 for each year. This is set by statute and appropriation levels are approved by the General Assembly for these annual periods only.

	FY 83	FY 84	FY 85	FY 86	FY 87
Case Coordination	---	---	19,270	31,946	46,707
Day Program/Adult	---	111,726	188,621	353,159	379,958
Day Program/Child	139,823	138,500	145,700	175,640	150,502*
Habilitation	239,430	221,514	158,839	302,640	389,040
Child Group Home	164,549	171,164	218,996	189,267	193,422
Adult Group Home	---	21,519	274,962	294,527	298,149
Leisure/Family Support	14,500	---	30,000	59,108	74,653
DDSA Start-up	67,000	---	---	---	---
Administration	---	39,986	11,159	58,590	87,668
TOTAL	**$ 625,302**	**$ 704,409**	**$1,047,547**	**$1,465,237**	**$1,620,099**

* The decrease in day program funding for children reflects the assumption of funding responsibility for these programs by ISBE.

As can be seen above, the financial commitment to programs targeted for autism has increased significantly since FY 1983. This increase, nearly tripling the amount of funds targeted to autism agencies, is significant in view of the fact that it occurred during time of decreased revenues and limited increases to the Department budget. Although other programs in the Department were increased during this period, none experienced the same rate of growth. The priority of allocating funds to autism thus occurred within limited resources.

The total dollar amount prioritized for autism does represent a small part of the DMHDD budget now; this is in part due to the low incidence of the disability. Nonetheless, later sections of this report will speak to areas in which dollar allocations should be increased for persons with autism.

Some further explanation of the above numbers is needed:

Case Coordination: Includes one time awards to Blare House in FY 1985 and to Illinois Center on Autism in 1986 and 1987.

Day Program/Adults: This category includes not only the more traditional developmental training programs but also vocational development and supported employment. Funds in this category have tripled since FY 1983. This increase will be even larger as the developmental training grant for RRAF proposed for this year is not included in the above figures.

Day Programs/Children: These include specialized programs for children not served by public school programs. These programs are operated by Illinois Center for Autism and Rimland School. The State Board of Education provides major funding for these educational programs.

Habilitation: This category includes what is typically known as special habilitation and is available to deal with specialized behavior needs. Funds are approved on a case by case basis and are time limited if funded through a purchase care arrangement. Grant funded habilitation support provides care for ongoing needs and is not time limited.

Child and Adult Group Homes: These settings are typically small - six or fewer - and offer intensive 24 hour care. The residential settings have been described in previous sections.

Leisure/Family Support: This includes leisure time and in-home family support services as well as a foster care award.

DDSA Start-up: These are federal funds which are made available through the GPCDD. Funding is dependent upon the topic and the quality of the proposal submitted in a request for proposal (RFP) process.

Client Profile

Persons with autism currently being served by the Department fall into three categories: state facility residents, community recipients and clients served out-of-state. In order to learn more about the characteristics of these recipients, a profile was done using data from the Illinois Client Information System (ICIS). Staff are required to complete ICIS data for all state facility residents; ICIS data are also required for entering clients for grant funded community services.

In reviewing the data below, two important factors should be considered:

- First, the number of persons with a diagnosis of autism is artificially low. This may be due in part to misdiagnosis of autism which, as indicated earlier in this document, continues to be a problem. Additionally, some parents believe not identifying the autism syndrome

will enhance access to services due to perceived prejudices of the system against autistic clients.

- Secondly, ICIS as a system maintains an incomplete data base. Although ICIS face sheets must be entered for grant funded services, it is not mandatory for purchase care services. Also, many important data items are not required; therefore, for the reported individuals, some data may be unrecorded, blank, or miscoded.

The profile below should, therefore, be viewed as a **sample** rather than a total census of all individuals with autism served by DMHDD. The sample data do provide a profile of characteristics of autism and are reflective of the definition and description of autism used in the earlier part of this paper.

The most recent review of the ICIS data file (08/31/86) reports 617 individuals with autism as a primary, secondary, or tertiary disability receiving services from DMHDD. This includes 44 state facility clients, 564 community clients and 9 individuals currently served by out-of-state facilities. The distribution of community clients in the sample by regional areas, the percentage distribution of autistic clients, and the percentage distribution of the general population are arrayed below:

Region	# of Autistic Clients Reported	% of Autistic Clients	% of Total State Population
1 (Northwest Illinois)	107	19.0	13.6
2 (North/West Chicago Suburbs)	130	23.0	21.2
3 (Central Illinois)	48	8.5	12.1
4 (Southern Illinois)	63	11.2	10.6
5A (North Chicago)	76	13.5	12.0
5B (South Chicago)	83	14.7	14.3
6 (South Chicago Suburbs)	57	10.1	16.2
TOTAL	**564**	**100.0**	**100.0**

Appendix v lists the agencies which report serving autistic clients.

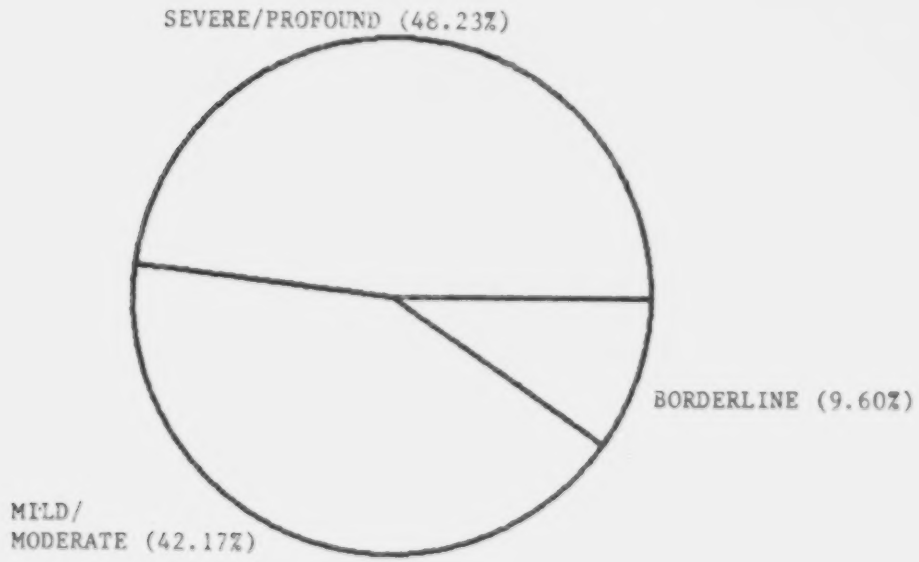
Of the sample data, 74% are males and 26% females. Over half, 52.4%, are under the age of 21, and 60% are white, 25% are black, and 15% are other backgrounds. The clients with autism served by DMHDD for the most part exhibit no primary physical impairments. Over 90% have normal vision and hearing and do not have mobility impairments.

Regarding the type of services these individuals now receive, the data base was mostly incomplete. ICIS does contain a question regarding current day programs. The responses to this question are contained in Appendix vii. In this category, a large number of responses were blank or miscoded. Of those reporting, the most common day program was adult or child developmental training.

Additional detail regarding the characteristics of clients with autism are arrayed below.

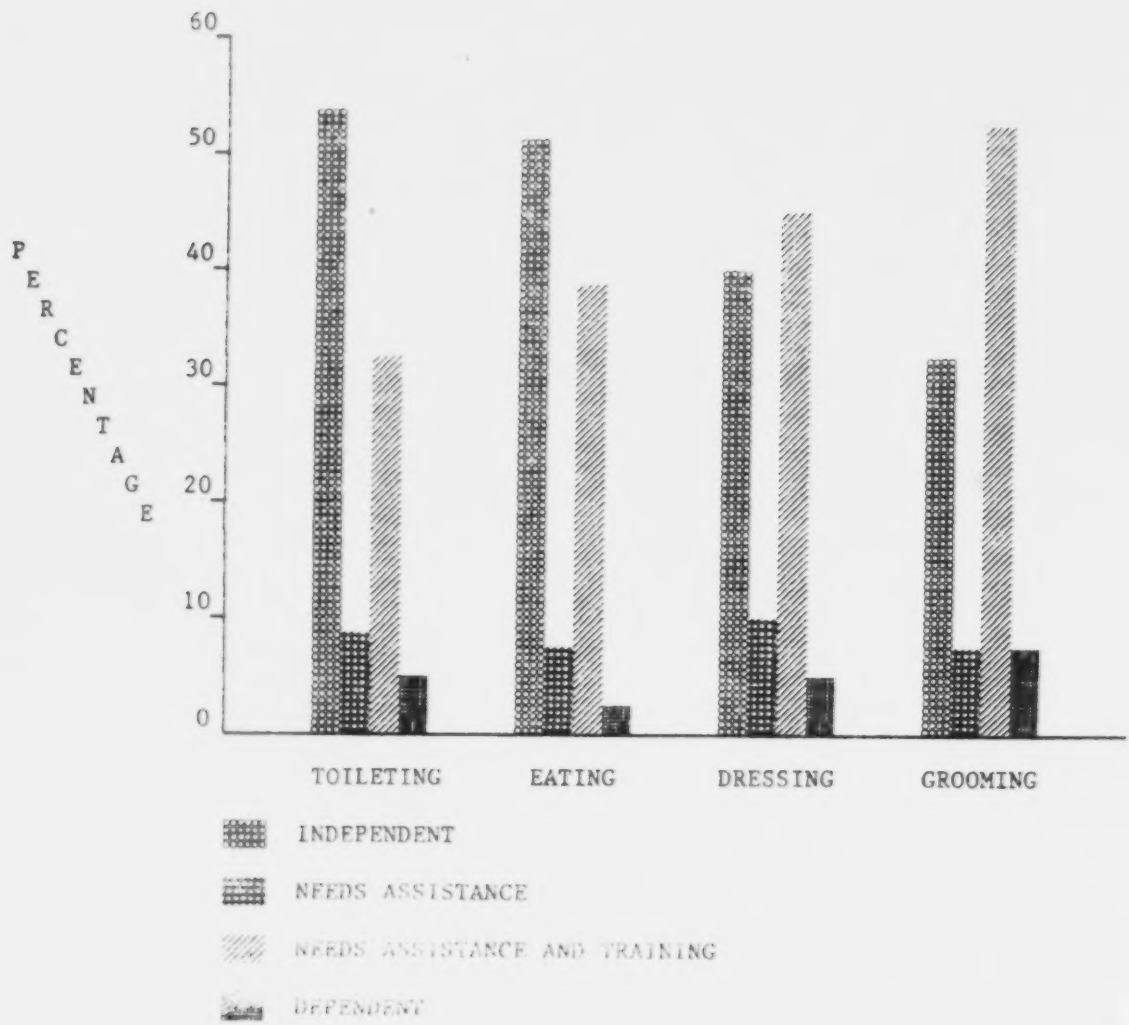
Level of Intellect

Of individuals with autism reported on ICIS, 9.6% were classified as either not retarded or borderline. Another 42.2% were mildly or moderately retarded and 48.2% of autistic clients were severely or profoundly retarded. This is consistent with national data on the level of mental retardation for persons with autism (See page 6). It should be considered that IQ testing is often not reliable for individuals with autism. Many agencies reported the level of severity to be greater than the data below indicate.



Activities of Daily Living

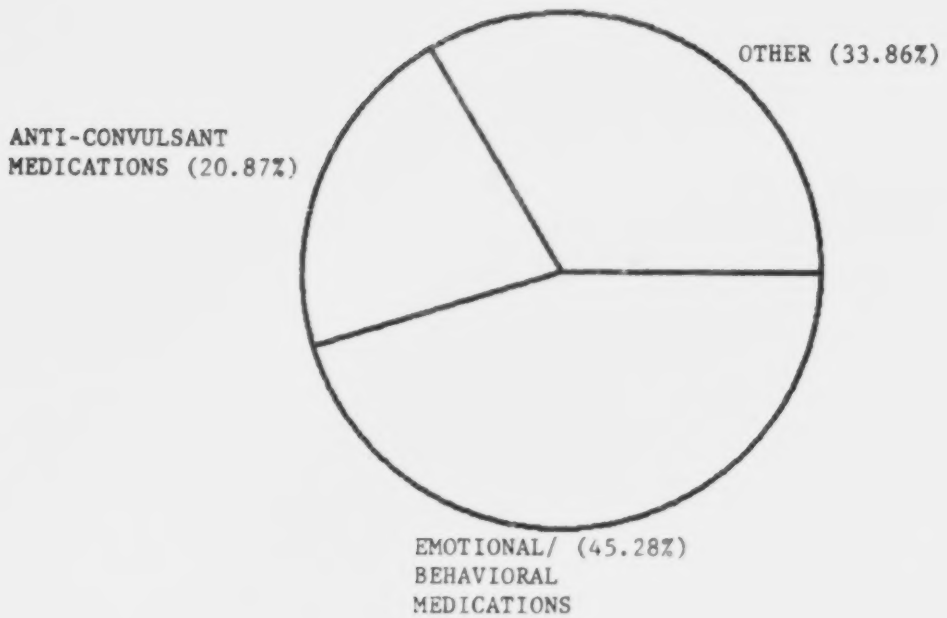
Individuals with autism served by DMHDD have training needs in the areas of toileting, eating, dressing, and grooming. Almost one half of the clients with autism reported on ICIS need assistance in toileting and eating skills, while 60% need assistance in dressing and two-thirds need grooming assistance.



Medications

ICIS data show that over half (54%) of the autistic clients receive medications. The most common types of medications are for emotional or behavioral problems. More specific information on drug type is not available from ICIS.

TYPES OF MEDICATIONS NEEDED



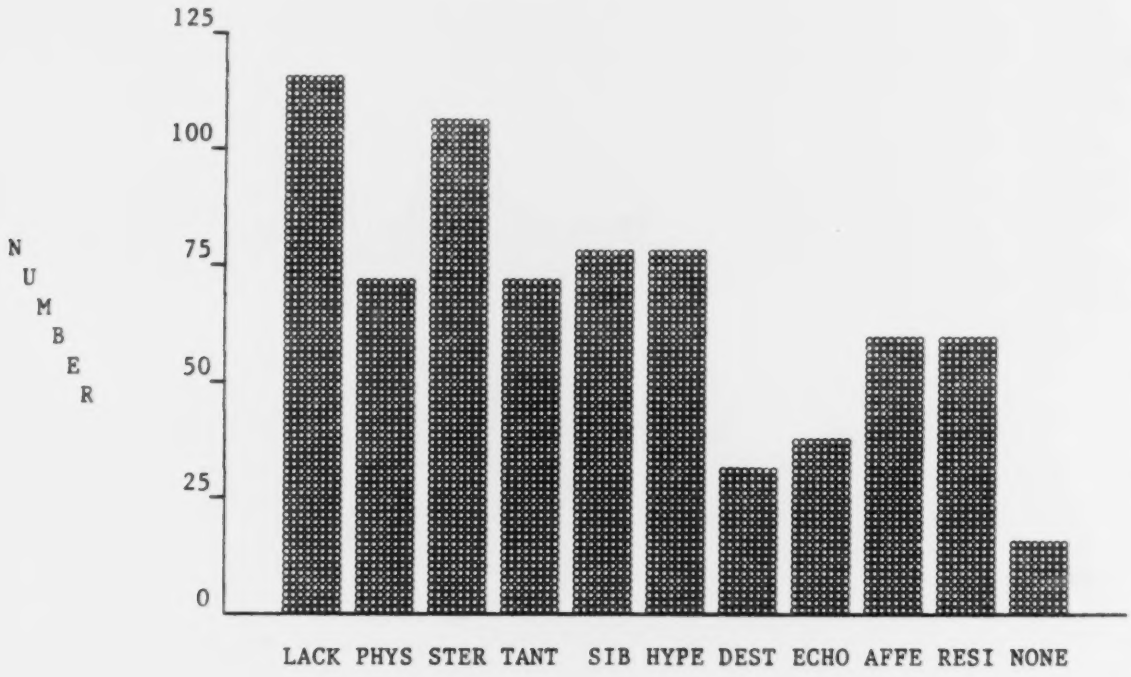
Of the individuals who need medication, 84% require assistance in administering the drugs. This large number is due in part to the inclusion of children, for whom assistance in taking medications is appropriate.

Medications Reported for Persons with Autism

Self-administered medication	15.8%
Medication with supervision	11.4%
Medication administered by others	72.8%
	100.0%

Behavioral Impediments

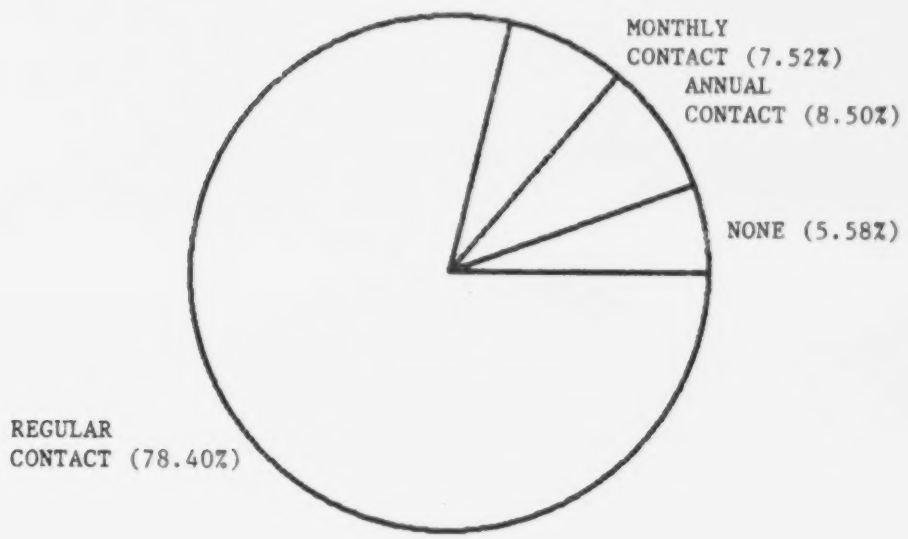
A variety of behavioral impediments are reported on ICIS for clients with autism. The most frequent of these are lack of social response, stereotypical and repetitive behaviors, as well as tantrums, self injurious behavior and hyperactivity. These, of course, are consistent with the characteristics of persons with autism, as identified in Part One. The more commonly reported behavior problems are identified below by frequency. A single individual may have multiple behavior problems so these numbers do not total to a unduplicated client count.



LACK = LACK OF SOCIAL RESPONSE
PHYS = PHYSICAL ASSAULT
STERE = STEREOTYPICAL REPETITIONS
TANTR = TANTRUMS
SIB = SELF INJURIOUS BEHAVIOR
HYPER = HYPERACTIVITY
DESTR = PROPERTY DESTRUCTION
ECHO = ECHOLALIA
AFFE = APPROPRIATE AFFECT NOT DISPLAYED
RESI = ACTIVELY RESISTS SUPERVISION
NONE = NO BEHAVIORAL IMPEDIMENTS

Family Contacts

The degree of family involvement with clients reported in the sample is quite high. Of those for whom this data item was completed, 323 individuals with autism had regular contact with families, representing 78% of the sample for this item. Only 23 persons maintained no contact with families, while 31 and 35 respectively had monthly or annual contacts with family. These data confirm the high degree of family interaction with persons who have autism and affirm the need for family assistance programs.



Exemplary Programs

Some of the model programs described below were identified by the Center on Human Policy, Division of Special Education and Rehabilitation at Syracuse University. The Center was federally funded to locate programs across the United States "demonstrating model practices for integrating people with severe disabilities, including autism, into the community." Programs were nominated by a panel of national experts on community services, project staff members, and by responses to a published request in national newsletters. Through a combination of telephone interviews, review of written materials, and selected on-site reviews, model programs were selected that provided "promising" practices in assisting persons with severe disabilities. Additional model programs were identified through articles, highlighted programs in national newsletters, other state mental retardation departments, and the key informants. These programs are listed below and a brief description of each program is contained in Appendix viii. It should be noted that this list is not intended to be inclusive of all model efforts but is intended to present illustrative highlights of programs successful in dealing with characteristics of autism.

Autism Service System Dr. Ruth Sullivan, Director	Huntington, West Virginia
Autism Services Association Ed Burke, Director	Weston, Massachusetts
Chestor House Dan Fairchild, Director	Boulder, Colorado
Community Services for Autistic Adults and Children Patricia Juhrs, Director	Rockville, Maryland
Council of Organizations and Schools for Autistic Children and Adults, Inc. Nancy Richardson, Director	Lawrenceville, New Jersey
Appropriate Living for Autistic Joan Flicker, Director	Wyckoff, New Jersey
Division TEACCH Dr. Eric Schopler, Program Director & Co-Founder	Chapel Hill, North Carolina
Jay Nolan Center Tom Thompson, Director	Los Angeles County, California
Residential Care for the Developmentally Disabled, Inc. Dorrie Lee, Program Director	Oshkosh, Wisconsin

Characteristics Common to Exemplary Programs

The Community Integration Project of Syracuse University summarized characteristics which were common to model programs serving people with challenging behaviors. Because their conclusions paralleled other model programs reviewed for this report, the Syracuse University findings are summarized below. Additional comments on model programs will follow the University summary.

- First, the program search revealed that "behavior" problems are not a reason for preventing people from living in typical homes in communities.

- Best services for people with challenging behaviors were provided by agencies with a commitment to community integration.

- Model programs contained an ecological perspective on behavior, i.e., behavior is caused by an interaction of all elements present in the environment where it is exhibited.

- Without exception, model programs serving people with challenging behaviors operate small residential settings. Fewer people allows more control over life-space and also allows staff to become more familiar with residents.

- Small agencies are also a characteristic of model programs reviewed by the University project. By restricting growth, the agency staff were able to be more directly involved with the clients served. Most programs limit residential capacity to 4 to 6 individuals.

- Heterogeneous groupings of individuals were a characteristic of these programs. This was viewed as nearly as important as small size. These programs did not group problem behaviors in a single location.

- Individualization was a key element in the model programs. This allows structuring programs to the specific needs of individuals as opposed to fitting individuals to a predetermined array of programs. Individualization is believed to be directly tied to the quality of programming.

- Flexibility by provider agencies to offer individualized care was a factor in model programs. This means both flexibility in policies and procedures and in funding methodologies.

- Positive interventions were generally used by model agencies in dealing with challenging behaviors.

- Model programs provided an effective array of services to support the residents' needs and care provider's capability. These support services include 24-hour on call crisis intervention, in-home behavior consultants, respite care, homemaker aides, foster home supports, and small case management caseloads.

- Recognition is given to the role played by the direct care staff in the development and implementation of an individualized service plan. Emphasis was placed on the trust placed in those direct care staff carrying out the day to day activities. The direct care and professional staff are thus mutually supportive rather than hierarchical.

Staff Training

One characteristic common to most of these model programs is specialized staff training. All staff are actively involved in planning and facilitating habilitation. A highly recommended training model which has been used in several states and in some cases in Illinois is National Personnel Training. This model was originally developed in conjunction with NSAC. Ann Donnellan, Lou Brown, and Gary LaVigna are national trainers associated with NPT. The NPT program contains six modules which provide training in assessment procedures, characteristics of autism, instructional and behavioral techniques, communication, and program planning. Training is provided for 13 days to "train the trainers." These individuals, in turn, provide instruction to a second group of key staff. The advantage of this training model is that it is able through a single training program to generate a large local talent pool.

Staffing Patterns

All the model programs have some type of special staffing ratios, which are responsive to the needs of persons with autism and which reflect the size of the residential program. Most call for an intensive staff ratio of one staff to one or two residents during peak times. These special staffing ratios can be and are reduced over time as behaviors come under control and independence increases.

Medical Support

The model programs provided comprehensive medical support including a good neurologist, nutritionist, general practitioner and dentist. As an example, Community Services for Autistic Adults and Children in Rockville, Maryland routinely provides dental screenings for their clients two or three times a year and provides checks with doctors for erratic behavior. Since many individuals with autism develop seizures during adolescence and also need medications, access to good psychopharmacology and neurology is critical. Nutrition becomes especially important as individuals undergo medication reduction.

Respite Care

Model programs recognize the need for parents of autistic children and adults to receive in-home intervention and assistance. As an example, the Jay Nolan Center in Los Angeles, a nationally recognized model, provides respite care to approximately 800 families. This includes out-of-home day respite on Saturdays which offers a recreational program from 9 AM to 3 PM at school sites. It also provides extended year educational and leisure programs. Finally, The Center also provides in-home respite through the use of specially trained sitters.

Adult Work Programs

One of the principles which experts subscribed to was that people with autism should be integrated into normal work environments. The model programs, with very few exceptions, offered opportunities for supported work or supported employment. The goal was clearly to provide everyone with an integrated work setting.

Residential Services

Residential services in the model systems are available within the individual's native community or in reasonably close proximity to his/her family. Thus there is local accountability, ability to maintain close family ties, and parent and consumer participation in the design, operation and monitoring of services. The best community living arrangements are family-scale, are integrated into typical neighborhoods, and encourage the development of close, ongoing social relationships both within the residence and in the community.

Many agencies operate group homes smaller than four-bed; for example, the Autism Services Center in Huntington, West Virginia, maintains two homes which serve only one client.

Early Childhood Programs

Early childhood programs are designed to meet the physical, sensory, communication, cognitive, and emotional needs of children with disabilities age birth to three. In addition to direct service to children, parents are also actively involved in training to facilitate ongoing development of the child.

Attributes of programs that are successful in early childhood autism stress well trained personnel, family networking and early integration with other non-handicapped children. For the past four years, the Kentucky Center for Special Children's Services has provided an integrated environment for autistic children in the Louisville area. This involves careful oversight by administrators to ensure a proper ratio or degree of integration with other programs. According to the Center, benefits of early integration offered by this program have been demonstrated.

Research appears to support this conclusion by Center staff. Fredericks, et al. (1978) concluded that given proper preparation, moderately and severely handicapped preschoolers can experience gains in an integrated setting. Research in 1986 by William and Susan Stainback of the University of Northern Iowa found no detriments reported for either group of children in integrated settings.

Overall, family support, involvement, and training were seen as key elements of early intervention programs.

Funding Methodologies

Programs are currently funded by the Department of Mental Health and Developmental Disabilities through two primary mechanisms:

- Grant-in-aid: Grants are disbursed to agencies in advance monthly allotments. The monies are awarded for a specific service according to a previously submitted agency plan and proposed budget. The budget identifies total costs, number of service units and computed cost/unit. Unusually high unit costs require justification based on special needs of the population. Grant categories such as demonstration or administration are sometimes used to supplement costs of programs serving a special needs population.

  The advantages of a grant system are that funds are distributed in advance of service delivery and that negotiation of proposed budgets allows variations for service needs. This provides more flexibility for individual needs, but does reduce accountability on a case-by-case basis.

- Purchase of care: Funds in this category are paid to agencies after service delivery based upon a predetermined rate per unit of service. The rate is based upon a methodology that considers proposed or actual costs of operations. In the case of adult residential settings, such as the Community Residential Alternative (CRA) or the Home/Individual Program (H/IP), a rate ceiling is established at the 70th percentile of total reported costs for all agencies, meaning that the state pays the full cost for programs whose costs are up to the 70th percentile; those agencies whose costs are higher receive only the maximum rate. The incentive is to reduce costs to the 70th percentile ceiling. The ceiling is adjusted for geographic areas, as costs may vary by regions in the state. This approach does group agencies serving high need clients with low need clients and does not separate special population agencies for comparison purposes.

  A more detailed explanation of the CRA rate methodology is contained in Appendix ix; the same method applies to H/IPs.

  The significance of the ceiling approach is that it does not allow for consideration for special needs above the maximum. The basis for this was that needs which exceeded ceilings would require care in excess of that available in communities and would therefore need more structured settings. Agencies with unique costs above the ceiling were only able to address more intensive staff needs through supplementation of rates by ancillary and time limited services.

  An example of these time limited services is special habilitation services, program codes 91-V or 96-V, which allow for behavior intervention on a time limited basis. The duration of services does not typically extend beyond six months for 91-V or one year for 96-V. The coverage of ongoing behavior needs are thus limited by this approach. Special habilitation funds have also been provided through a grant-in-aid mechanism.

PART FOUR
SERVICE NEEDS FOR AUTISM

Based upon the review of client characteristics and model programs, the following list of service needs for the autistic population can be identified.

Family Programs and In-Home Behavior Management

In conjunction with day programs there must be a home-based program that helps families handle problems arising in the home environment and that provides consistency in behavioral programming for the autistic individual. Parents and siblings benefit from training in behavior management, language and communication, and medical management. Families can receive support through counseling, networking with other families, and receiving help with planning for the autistic individual's future. Most importantly, in-home and out-of-home respite services are critical in maintaining individuals with autism in the home.

Diagnostic Assessment

A full interdisciplinary diagnostic assessment is a necessity. Since the onset of autism is typically before 30 months of age, immediate and accurate diagnosis is essential when problems are suspected, so that appropriate early intervention can begin. Assessment should include delineation of assets and deficits, behavioral analysis, language evaluation, and medical and dental screening. Periodic reassessments are required by changing problems and circumstances. For example, during transition from school programs to adult programs some families have noted instances where higher functioning autistic individuals were misdiagnosed as mentally ill rather than autistic. They also report hesitance to diagnose and label adults as autistic as it may exclude them from generic adult developmental disability services.

Case Coordination

The ability to identify service needs consistent with identified client problems, to link people to available resources, and to monitor the provision of services are key functions of case coordination units. This service must be available for persons with autism in order to ensure appropriate service delivery. Specialized training on autism needs to be given to case coordinators to increase their effectiveness with this population.

Educational/Vocational/Employment Programs

Classrooms and vocational settings specifically designed for autistic individuals may be necessary. While segregated programs are not necessarily preferable, they have the advantage of having the expertise and specialized programming required to teach these individuals. Programs designed more generally for developmentally disabled people have often excluded the more severely disturbed autistic individuals from their programs. In terms of integration in non-handicapped settings, DeMyer (1982) estimates that only 10% of autistic children can be accommodated satisfactorily in a classroom with

normal age mates, even after intensive therapy. However, the Louisville School for Autistic Children in Kentucky has been able to successfully integrate all its students with autism into the regular public school system. Community integration is not an all or nothing issue. For instance, children can be mainstreamed in some classes or recreational programs and not others.

It is generally recommended that educational classes specifically for autistic children include the following:

- Structured, intrusive, behavioral methods
- Small numbers of students
- Higher teacher/student ratios than in other developmental disability classes
- Programming year-round
- Linkages between school and home and close family involvement
- Emphasis on communication

The key is not only the curriculum but also having special educators who are trained to work with students who have severe behavioral and communication problems. Most special education training programs only touch on behavior modification and communication and thus teachers do not have the levels of skills needed for behavior analysis, program design, data collection, and program evaluation.

Although this category is most important for needs of autistic persons, the DMHDD will reserve recommendations in this category to the study currently underway with ISBE.

The transition from school to work is a difficult period for autistic individuals and their families. Due to the mandates of Public Law 94-142 (Education of All Handicapped Children Act), the school age child's needs are more likely to be met than those of the adult. Vocational program staff are often not willing, prepared, or trained to handle the behavior problems of autistic young adults.

Work opportunities such as supported employment and supported work need to be considered for persons with autism. In some cases, individuals graduating from public school programs may be capable of directly entering a work program. However, the majority of persons with autism could not function independently on a job without ongoing supervision. Yet there is no reason to keep them separated from the general work force as long as trained supervisors ("job coaches") are there to manage behaviors. Other day programming options which are used include adult day programs, developmental training, sheltered workshops, and work activity.

Residential Programs

In most circumstances it is preferable for younger autistic children to live with their families, but in some circumstances due to family stresses and extreme caretaking demands, residential placement may be needed. As autistic children get older, this need for residential care increases.

For adults, institutional care, which may be inappropriate, is often the only option available. Estimates by Dr. Ruth Sullivan are that most autistic adults reside in institutional settings. The physical size of adults and their behavioral difficulties may create significant management problems for their families. This is why a focus on more resources for the children is needed so that their behaviors do not escalate as they become older. Also, as parents age and families experience illness, deaths, and divorce, they may be less able to care adequately for the autistic adult. For those individuals requiring placement outside the natural home, it is clear that integrated community living in small group homes is the most appropriate option.

Public Education/Awareness

Community acceptance is a major problem for individuals with autism, particularly due to their severe behaviors (e.g., aggressive, self-abusive). These behaviors often result in their exclusion from both generic and developmental disability community programs and services. If persons with autism are going to be physically and socially integrated and not institutionalized, then public education is needed. This can be done in conjunction with other public information programs more generally about developmental disabilities, by adding a component on autism. Public relations material from advocacy associations can also help foster community acceptance of these individuals.

Professional/Paraprofessional Training

Specialized professional training regarding autism is needed because very few professionals, in <u>any</u> discipline, have the knowledge and technology to effectively serve persons with autism. Although autism is a severe disorder, it is of low frequency, and hence is often neglected in university training programs. Many times, the behaviors seen in these individuals are only partially attributable to the condition. Poor behavioral programming due to insufficient expertise in professionals may exacerbate these behavioral problems. Professional/paraprofessional training efforts need to include university-sponsored staff in-service training and ongoing networking between professionals in the field.

PART FIVE
RECOMMENDATIONS

In order to enhance the quality of care provided to persons with autism and to ensure that appropriate services are developed, the following actions are recommended.

1. **Ensure proper identification of autism by increasing the knowledge of autism among parents and professionals and increasing general public awareness of the syndrome.**

Implementation Plan

- Develop a resource manual that will increase public awareness as well as parental and professional awareness of the characteristics of autism and available services within the state. In New Jersey, the Developmental Disabilities Council developed a pamphlet which contained a list of resources throughout the state for evaluation and early diagnosis of disability. A similar resource document should be developed in Illinois.

- The distribution of this resource document should include physicians, health care professionals, psychologists, service providers, case coordinators, and parents.

- The state should designate existing multipurpose and interdisciplinary facilities in Illinois to develop diagnosis and assessment capability for autism. These centers should be available for conducting comprehensive evaluations of persons with severe behavior or communication disorders and for consultation by case coordinators. The low incidence of autism limits the feasibility of establishing new diagnostic programs for the sole purpose of autism.

- Training should be provided to diagnosticians in existing facilities and case coordination agencies to enhance their knowledge and understanding of autism.

2. **Assure the availability of early intervention services for children with autism and their parents so that intervention can occur at the earliest possible time.**

Implementation Plan

- In line with the approach taken by model programs, early intervention for children with autism should occur whenever feasible in programs which are not exclusively for autism. Often autism is not identified at this early age, but options for parent involvement in training and infant stimulation must be provided.

- Programs should emphasize an interdisciplinary and individualized approach in carrying out training to enable children with a variety of disabilities to be served.

- In carrying out the above objectives, it is especially important that the staff in early intervention programs receive appropriate training in dealing with characteristics of autism (see Recommendation #3).

3. **Establish an ongoing training system for agencies and parents to provide expertise in the area of autism.**

Implementation Plan

- Resources should be provided to assure in-service training for professional and direct care staff who work with severely disabled and autistic children and adults to ensure their understanding of the care and teaching techniques for persons with autism. This training should be provided to all new employees and periodically thereafter. Training should be available in both state facilities and community agencies. High quality in-service training programs currently operated by Illinois community agencies should be considered for dissemination to other facilities. In addition, training models operational in other states should be considered for application in Illinois. Two such programs are the National Personnel Training of Ann Donnelan, Lou Brown, and Gary LaVigna, and the TEACCH program directed by Eric Schopler. It is further recommended that a training complement be established within the state to provide ongoing and on-site training. A "train the trainer" approach is highly desirable for use due to the ability to train larger number of persons from a small initial training complement.

- Training should be made available for parents and siblings as well to encourage their active involvement in the care of their children and to recognize their value as in-home therapists. In fact, many experts believe parent and family training may be the key element in programming for autistic children, due to the extent of time spent with the child. Again, the TEACCH model trains parents to work with their children in managing behavior problems and improving language, social, and learning skills.

4. **Enhance family support mechanisms to enable persons with autism to remain in the home environment.**

Implementation Plan

In a needs survey conducted by the Governor's Planning Council on Developmental Disabilities, respite care services were identified as the most urgently needed family support service for persons with developmental disabilities. It is clear that the availability of respite care contributes to the stability of families who keep their children at home. Specific implementation tasks are:

- A special model of respite care is needed for families with autistic children that allows for more intensive support and follows the concepts of respite provided in model programs. This includes trained respite sitters, day respite for weekends, and after school or after work programs. Further, a consistent standard is needed in the number of hours

allotted for respite care. As an example, the Appropriate Living for Autistic (ALFA) program, a member of the COSAC in New Jersey, develops a respite schedule in advance which typically includes 25 to 40 hours per month of in-home care. In some cases of high need, maximum hours must be determined on a case by case basis.

- Particular emphasis must be placed on the availability of respite care for adults with autism as many areas of the state and some provider agencies do not offer such care. Emergency respite or temporary residences must also be available to families of children with autism thus avoiding a permanent placement of the child away from the home, but allowing an urgent need to be readily addressed.

- Respite workers should receive specialized training in the care of persons with autism.

5. **Ensure an adequate transition from public school programs to adult work and day programs for persons with autism and provide day services to adults currently unserved or not appropriately served.**

Implementation Plan

As indicated earlier, this report does not address in detail the transition and public school program issues for individuals with autism. However, the significance of the issue facing parents with adolescents and teenagers who are autistic does necessitate its inclusion in this report.

- It is generally recommended that transition planning begin in early adolescence to facilitate access to adult services. It is further recommended that transition planning for persons with autism emphasize participation in work or supported employment programs to the degree possible.

- The availability of adult work and day programs should be targeted to geographic areas demonstrating greatest current need and ability to document clients who are now or within the next three years will be graduating from public school programs. The work models developed, both in Illinois and in other states, should be considered for replication.

6. **Ensure that individuals with autism are afforded opportunities to reside in alternative settings which maximize potential for growth and offer a least restrictive and age appropriate setting.**

Implementation Plan

- It is recommended that residential settings for persons with autism be increased. These settings must be small (no larger than six) and funding methodologies must be flexible enough to allow for more intensive staff ratios on an ongoing basis. Special behavior programming should also be available on a case-by-case basis to deal with the short-term and intermittent needs of persons with severe behavior problems.

- DMHDD should continue to require that group homes for persons with autism be licensed as Community Residential Alternatives (CRAs), but that implementation of programming be individualized and adapted to more intensive client needs. Residential programs should promote normal daily living and make use of community resources.

- Autism should be targeted in request for proposal development to assure expansion of community residential group homes within overall Department growth of residential settings.

- Group home staff should receive special training in skills needed to care for persons with autism. This should include both in-service and pre-service training.

Fiscal Considerations

To carry out many of the above recommendations, increased revenues will be needed to expand the DMHDD budget. The Department recognizes that the dollar amounts will be contingent upon the limits in state revenues. A commitment is given, however, to target a portion of FY 1988 budget increases, exclusive of cost of living, to enhance services to persons with autism.

It is further recognized that the above strategies will call for multi-year implementation. The recommendations thus assume that future year funding will be needed to continue to address the needs of the current clients and those "aging out" or graduating from public school programs.

Finally, the request for resources to support family care and enhance employment and community integration opportunities for persons with autism must be contrasted with the cost of the alternatives: state facility or nursing home care for the majority of the population. If even a portion of the estimate of 90% institutionalization for autistic adults were to occur in Illinois, the long run costs would be staggering. State facility per annums currently average over $40,000 per developmentally disabled resident. In contrast, the average cost per person of the Medicaid waiver initiative, a program which offers a comprehensive package of residential, day program and community support services, is estimated to be $27,000 in this fiscal year. Thus, the most expensive community package still falls far short of the typical state facility cost.

The options recommended herein are even less costly than the Medicaid community initiative. If only respite care, parent training, or day programs are needed, it is likely that costs would range from $3,000 to $18,000 per client. The implementation of training also offers a relatively low cost option which can help a greater number of individuals.

CONCLUSION

The philosophy of autism programs is to assure dignity and community presence at the maximum level of independence for individuals with autism through services which incorporate the following dimensions:

- Early identification of the syndrome;
- Support services to schools and human service agencies;
- Assistance in securing and retaining optimal employment or work opportunities;
- Facilitation of placement in the least restrictive community setting;
- A network of resources for professionals and families;
- Anticipated support of a lifelong duration.

The Department's report on the service needs of persons with autism thus calls for stronger support of families in their efforts to maintain autistic children and adults in the home and more individualized consideration of service options. The report emphasizes the need for flexibility in the system to deal with the unique needs of the autistic population. The report additionally calls for recognition of the need for adult residential care and corresponding changes in funding methodologies. The implementation of these recommendations will facilitate the opportunity for persons with autism to learn, grow and work in a supportive environment.

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Appendix i

National Society for Autistic Children
Definition of the Syndrome of Autism

Essential features: Autism is a behaviorally defined syndrome. The essential features are typically manifested prior to 30 months of age and include:

1. Disturbances of developmental rates and sequences. Normal coordination of the three developmental pathways (motor, social-adaptive, cognitive) is disrupted. Delays, arrests, and/or regressions occur among or within one or more of the pathways a) within the motor pathway (e.g. gross motor milestones may be normal, while fine motor milestones are delayed); b) between pathways (e.g. motor milestones may be normal, while social-adaptive and cognitive are delayed); c) arrests, delays and regressions (e.g. motor development may be normal until age 2 when walking stops; some cognitive skills may develop at expected times, while others are delayed or absent; imitative behavior and/or speech may be delayed in onset until age 3, followed by rapid acquisition to expected developmental level).

2. Disturbances of responses to sensory stimuli. There may be generalized hyperreactivity or hyporeactivity and alternation of these two states over periods ranging from hours to months. For example a) visual symptoms. These may be close scrutiny of visual details, apparent non-use of eye contact, staring, prolonged regarding of hands or objects, attention to changing levels of illumination; b) auditory symptoms. These may be close attention to self-induced sounds, non-response, or overresponse to varying levels of sound; c) tactile symptoms. These may be over- or underresponse to touch, pain, and temperatures, prolonged rubbing of surfaces, and sensitivity to food textures; d) vestibular symptoms. These may be over- or underreactions to gravity stimuli, whirling without dizziness, and preoccupation with spinning objects; e) olfactory and gustatory symptoms. These may be repetitive sniffing, specific food preferences, and licking of inedible objects; f) proprioceptive symptoms. These may be posturing, darting-lunging movements, hand flapping, gesticulations, and grimaces.

3. Disturbances of speech, language-cognition, and nonverbal communication. Symptoms may include a) speech (e.g. mutism, delayed onset, immature syntax and articulation, modulated but immature inflections; b) language-cognitive capacities such as rote memory and visual-spatial relations intact with failure to develop the use of abstract terms, concepts, and reasoning, immediate delayed, negative echolalia with or without communicative intent, nonlogical use of concepts, neologisms; c) nonverbal communication (e.g. absence or delayed development of appropriate gestures, dissociation of gestures from language, and failure to assign symbolic meaning to gestures).

4. Disturbances of the capacity to relate appropriately to people, events, and objects, manifested by a failure to develop appropriate responsivity to people and assignment of an appropriate symbolic meaning to objects. For example a) people. Absence, arrests and/or delays of a smiling response, stranger anxiety, anticipatory response to gestures, playing "peek-a-boo", playing "patty-cake", and waving "bye-bye", reciprocal use of eye contact and facial responsivity, and appropriate reciprocal responsiveness to physical contact, a failure to develop a relationship with significant caretakers or an excessive reliance on caretakers. For example, caretakers may be treated indifferently, interchangeably, with only mechanical clinging or with panic on separation. Cooperative play and friendships (usually appearing between age 2 and 4) may not develop. Expected responses to adults and peers (usually appearing between ages 5 and 7) may develop but are superficial, immature, and only in response to strong social cues; b) objects. Absent, arrested and/or delayed capacities to utilize objects and/or toys in an age-appropriate manner and/or to assign them symbolic and/or thematic meaning. Objects are often used in idiosyncratic stereotypic and/or perseverative ways. Interference with this use of objects often results in expressions of discomfort and/or panic; c) events. There may be a particular awareness of the sequence of events and disruption of this sequence may result in expressions of discomfort and/or panic.

NSAC
THE NATIONAL SOCIETY FOR CHILDREN AND ADULTS WITH AUTISM

INFORMATION AND REFERRAL SERVICE

NSAC
THE NATIONAL ADVOCACY ORGANIZATION SERVING PEOPLE WITH AUTISM AND THEIR FAMILIES

AUTISM is a severely incapacitating lifelong developmental disability that typically appears during the first three years of life. It occurs in approximately *fifteen out of every 10,000 births* and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism.

The symptoms are caused by physical disorders of the brain. They include:

(1) Disturbances in the rate of appearance of physical, social and language skills.

(2) Abnormal responses to sensations. Any one or a combination of senses or responses are affected: sight, hearing, touch, balance, smell, taste, reaction to pain, and the way a child holds his or her body.

(3) Speech and language are absent or delayed, while specific thinking capabilities may be present.

(4) Abnormal ways of relating to people, objects and events.

Autism occurs by itself or in association with other disorders which affect the function of the brain such as viral infections, metabolic disturbances, and epilepsy.

It is important to distinguish autism from retardation or mental disorders since diagnostic confusion may result in referral to inappropriate and ineffective treatment techniques.

The severe form of the syndrome may include extreme self-injurious, repetitive, highly unusual and aggressive behavior.

Special educational programs using behavioral methods have proved to be the most helpful treatment.

Autism is treatable—early diagnosis and intervention are vital to the future development of the child.

The accompanying chart visually portrays the more important signs and symptoms of autism. If a child exhibits seven or more of the symptoms listed above and in the chart and if the bizarre behavior is constant and inappropriate for the child's age, further evaluation is recommended.

Appendix ii

IIDD Prevalence Estimates

ESTIMATED PREVALENCE OF MENTAL RETARDATION, CEREBRAL PALSY, EPILEPSY, AND AUTISM IN ILLINOIS (TOTAL GENERAL POPULATION: 11,426,518)

	0-3	4-21	22-64	65+	Total
General Population	680,177	3,430,146	6,054,310	1,261,885	
Prevalence of:					
[1] Mental Retardation (moderate to profound)	3,656	18,168	25,595	2,742	50,161
Moderate	2,171	10,855	15,312	1,600	29,938
Severe	1,143	5,485	7,770	914	15,312
Profound	348	1,828	2,514	229	4,919
[2] Cerebral Palsy (all cases)	2,171	9,141	14,969	343	26,624
[3] CP Only	1,485	2,285	3,428	114	7,312
[4] CP and MR	571	6,399	11,084	343	18,397
[5] CP and EP	457	3,885	4,342	<100	8,784
[6] Epilespsy (all cases)	1,714	9,255	22,167	685	33,821
[7] EP Only	1,028	1,485	4,114	<100	6,727
[8] EP and MR	571	7,427	18,168	571	26,737
[9] Autism	114	2,514	1,143	114	3,885
[10] Estimated Prevalence of All Developmentally Disabled Persons in Illinois					114,492

TECHNICAL NOTES

1 Projected from an estimate range of 414/100,000 (Baroff, 1983) to 460/100,000 (New York Office of Mental Retardation Services).

2 All cases of Cerebral Palsy regardless of concomitant disabilities. Projected from an estimated range of 116/100,000 (from ICIS data) to 350/100,000 (Estimate of U.S. Department of Health and Human Services).

3 Estimate from ICIS data, of the number of developmentally disabled persons with cerebral palsy and no other handicapping conditions.

4 Estimate from ICIS data of the number of developmentally disabled persons with cerebral palsy and mental retardation.

5 Estimate from ICIS data of the number of developmentally disabled persons with cerebral palsy and epilepsy.

6 All cases of epilepsy, regardless of concomitant disabilities. Projected from an estimated range of 190/100,000 (Department of Health and Human Services estimate) to 400/100,000 (National Center for Health Statistics).

7 Estimate from ICIS data of the number of developmentally disabled persons with epilepsy and no other handicapping conditions.

8 Estimate from ICIS data of the number of DD persons with epilepsy and mental retardation.

9 Projections from an estimated range of 16/100,000 (ICIS) to 50/100,000 (Department of Health and Human Services).

10 The total figure of 114,492 represents a statewide <u>average</u> prevalence rate of 1%. The actual prevalence of developmental disabilities will be higher:

* among school aged populations,
* in areas experiencing serious economic decline, and
* in areas with higher levels of poverty than is found in the general population.

AUTISM

Prevalence Estimates Per 100,000[a]

I
(Rates in Service)

	Age Groups				
	0-3	4-21	22-64	65-	Total Population
-estimated rate	<.001%	.04%	.01%	<.001%	.016%
-estimated/100,000	<1	10.2	54%	<1	16
-New York rate	<.001%	.08%	.009%	<.001%	.031%
-New York/100,000	<1	24	6	<1	31
Retardation					
-estimated rate (% of all autistic)	.001% (30%)	.027%(76%)	.0076% (75%)	.000(0%)	.012(74.3%
-estimated/100,000	<1	7.7	4	0	12
-New York rate (% of Autistic)	<.001%	.050% (63%)	.008% (84%)	<.001%	.021%
-New York/100,000	<1	15	5	<1	21
No other disability					
-estimated rate (% of all autistic)	.001% (70%)	.009%(24%)	.002% (14%)	.000 (0%)	.004%(25%)
-estimated/100,000	<1	2.5	1.3	0	4
-New York rate	<.001%	.03% (35%)	.001% (14%)	<.001%	.009%
-New York/100,000	<1	8.4	1	<1	9.3

AUTISM-I Method: Jacobson, J.W. and Janicki, M.P. (1983). Observed prevalence of multiple developmental disabilities. Mental Retardation, V21(3), 87-94.

[a]Based on the following general population distribution: 0-3 (8.0%); 4-21 (30.0%) 22-64 (53%); 65+ (11%) among age groups.

AUTISM

Prevalence Estimates Per 100,000[a]

II
(Estimated from NSCAA)

Age Groups	0-3	4-21	22-64	65+	Total Population
-estimated rate		.14%	.16%	.13%	.15%
-estimated/100,000[a]	8	42	85	14	149
Severely retarded					
-estimated rate (% of all autistic)	.08%	(55%)	.09% (55%)	.07% (55%)	.083%
-estimated/100,000	5	24	47	8	84
Higher functioning					
-estimated rate (% of all autistic)	.06%	(45%)	.07% (45%)	.06% (45%)	.066%
-estimated/100,000	3	18	38	6	65

AUTISM-II Source: Wing, L. (1982). Children Apart: Autistic Children and their families. National Society for Children and Adults with Autism.

[a]Based on the following general population distribution: 0-3 (8.0%); 4-21 (30.0%); 22-64 (53%); 65+ (11%) among age groups.

Appendix iii

Key Informants and Consultants

Key Informants

Fran Bernstein
Blare House, Inc.
Morton Grove, Illinois

Evelyn Brehm
ISAC
Centralia, Illinois

Marsha Bronsen
ISAC
Centralia, Illinois

Joann Hamilton
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Peoria, Illinois

Jim Johnson
Arrise
Forest Park, Illinois

Rosemary Lapertosa
Resources for Retarded
and Autistic Families
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Carol Madison
Illinois Center for Autism
Fairview Heights, Illinois

Rosalind Oppenheim
Rimland School
Chicago, Illinois

Betty Outsen
ISAC
Kankakee, Illinois

Janet Welborn
ISAC and GPCDD
Wood Ridge, Illinois

Other Consultants

Tim Andriano
Planning Director
Governor's Planning Council
on Developmental Disabilities

Dr. Margaret Creedon
Consultant and Former Director
of the Child Development Center
at Michael Reese Hospital
Chicago, Illinois

Appendix iv

Listing of DMHDD Grant-in-aid and Purchase of Care Services

REVISED April 18, 1986

FY 1987 DD Service System

DD SERVICES

For FY 1987, all DD services funded by the Department of Mental Health and Developmental Disabilities, either Grant-in-aid, Purchase of Care or Title XIX Medicaid Home and Community-based Services Waiver, will be designated by a two or three digit reference number which, when paired with a fund code, if applicable, will identify services as separate programs for funding purposes.

Grant Funded Services (Fund Code 21)	Service (Program)	Reporting Mode
Service: Diagnosis and Evaluation - determination if, and to what extent, person has developmental disability through evaluation of present level of development abilities and needs, impediments to further development and cause of disability; recognition of services needed to enable the person to develop more independence	15	Event
Service: Client and Family Support - client or family training, individual and group client counselling, individual and group family counselling, sex education, genetics counselling, etc.	16	Event
Service: Vocational Development - time-limited services including, but not limited to, work adjustment training, vocational evaluation, skills training, placement training, etc.[1]	32	Day/Event
Service: Early Intervention 0-3 - diagnosis and evaluation, early intervention, stimulation, parent training and related activities for children 0-3 years old with significant developmental delays	33	Event

[1] Vocational Development may be day or event mode based upon agency and Region agreement.

Grant Funded Services (Fund Code 21)	Service (Program)	Reporting Mode
Service: Developmental Training I - training in which functional skills for daily living are developed through repetitive learning activities in training areas including, but not limited to, motoric development, dressing and grooming, toileting, eating, language, reading and writing, quantitative skills development, independent living and reduction of maladaptive behavior	34	Day
Service: Developmental Training I - training in which functional skills for daily living are developed through repetitive learning activities in training areas including, but not limited to, motoric development, dressing and grooming, toileting, eating, language, reading and writing, quantitative skills development, independent living and reduction of maladaptive behavior - co-funded by the Department of Mental Health and Developmental Disabilities and local education agencies	35	Day
Service: Developmental Training II - training in which skills for independent living are developed and enhanced through repetitive learning activities in training areas including, but not limited to, motoric development, dressing and grooming, toileting, eating, language, reading and writing, quantitative skills development, independent living and reduction of maladaptive behavior; may include limited preparatory skills training for persons whose developmental disabilities are so severe as to make their productive capacity inconsequential as defined in 29 CFR Part 525 et seq.	36	Day
Service: Developmental Training II - training in which skills for independent living are developed and enhanced through repetitive learning activities in training areas including, but not limited to, motoric development, dressing and grooming, toileting, eating, language, reading and writing, quantitative skills development, independent living and reduction of maladaptive behavior; may include limited preparatory skills training for persons whose developmental disabilities are so severe as to make their productive capacity inconsequential as defined in 29 CFR Part 525 et seq. - are co-funded by the Department of Mental Health and Developmental Disabilities and local education agencies	37	Day

Grant Funded Services (Fund Code 21	Service (Program)	Reporting Mode
Service: Regular Work - employment, anticipated to be long-term in a sheltered environment, for persons whose functional levels require a high degree of supervision but do not preclude future movement into supported or other competitive employment	38	Day
Service: Supported Employment - supervision, training, counselling, coaching, etc. to maintain persons in a worksite, typically in which persons without disabilities are employed	39	Event
Service: Special Programs - Dental Care	40	Event
Service: Special Programs - Additional support for Special Home Placement services	41	Not Applicable
Service: Special Programs - Additional support for Supported Living Arrangement services	42	Not Applicable
Service: Special Programs - Leisure Time	43	Event
Service: Special Programs - Additional support for Residential Respite services	44	Event
Service: Special Programs - Demonstration Project	45	Not Applicable
Service: Special Programs - Program Startup	46	Not Applicable
Service: Case Coordination - coordination of services including assessment of service need, development of individualized service plan arrangement for service delivery, coordination, advocacy with service provider(s), analysis of service network and followup	50	Event
Service: Generic Programs - Administration	74	Not Applicable
Service: Generic Programs - Transportation	77	Not Applicable

Purchase of Care Funded Services	Service (Program)	Mode
Service: Residential School - 7 day	91D	Residential
Service: Special Home Placement	91E	Residential
Service: Children's Group Home	91F	Residential
Service: SNF - Pediatrics	91I	Residential
Service: Community Living Facility	91J	Residential
Service: Community Residential Alternative	91K	Residential
Service: Residential Respite - time-limited services to persons in a residential setting, either planned or as the result of crisis, to reduce likelihood of, or prevent, long-term residential placement	91L	Residential
Service: Supported Living Arrangement	91M	Residential[2]
Service: Special Group Home	91O	Residential
Service: Group Respite	91Q	Event
Service: Family Home Maintenance - direct staff resources on a continuing basis to allow a person to maintain residence in the family home	91U	Event
Service: Special Habilitation - time limited services to persons in need of intensive habilitation or crisis behavior management to continue residence or secure residence in least restrictive setting	91V	Event

[2] Per diem rate established even though services typically not provided daily.

Purchase of Care Funded Services	Service (Program)	Mode
Service: Related Support	91X	Event
Service: Home/Individual Program	91Y	Residential
Service: In-Home Respite - time-limited services to persons and families, in the home, either planned or as the result of crisis, to reduce likelihood of, or prevent, long-term residential placement	91Z	Event

Waiver Funded Services (Fund Code 20)	Service (Program)	Mode
Service: Developmental Training I (previously described)	34	Day
Service: Developmental Training II (previously described)	36	Day
Service: Case Coordination (previously described)	50	Event
Service: Special Home Placement	96E	Residential
Service: Community Living Facility	96J	Residential
Service: Community Residential Alternative	96K	Residential
Service: Residential Respite (previously described)	96L	Residential
Service: Special Habilitation - services to persons in need of intensive habilitation or crisis behavior management to continue residence or secure residence in least restrictive setting	96V	Event
Service: Home/Individual Program	96Y	Residential
Service: In-Home Respite (previously described)	96Z	Event

Appendix v

Illinois Agencies Providing Services to Persons with Autism as Reported in ICIS, October 31, 1986

Agency	# Clients
Region 1	
Barbara Olson School of Hope	1
Children's Development Center	2
Fulton County Rehabilitation Center	1
Goldie B. Floberg Center for Children	1
Horizon House of Illinois Valley	2
Illinois Growth Enterprises	2
Knox County Council for Developmental Disabilities	32
Kreider Services	28
McDonough County Rehabilitation Center	5
Milestone	1
Ottawa Friendship House	2
Peoria ARC	14
Rock Island ARC	3
Rock River Valley Self Help Enterprises	1
Skills, Inc.	1
St. Francis School	1
St. Vincent School	3
Warren Achievement Center	7
Region Total	107

Appendix v (continued)

Region 2

Agency	# Clients
Arrise	13
Association for Individual Development	13
Blare House	7
Clearbrook Center	4
Countryside Association for the Handicapped	12
Community Support Services	16
Glenkirk ARC	14
Grove School	9
Helping Hand Rehabilitation Center	1
Lake County Society for Human Development	1
The Lambs	1
McHenry County ARC	4
North Shore Association for the Retarded	1
Northwestern University	1
Oak/Leyden Developmental Services	2
Proviso ARC	1
Rimland School	26
Seguin Services	3
Sheltered Village	1
Region Total	130

Appendix v (continued)

Region 3

Agency	# Clients
Aid to Retarded Citizens (Springfield)	3
Coles County Association for the Retarded	6
Crosspoint	4
Developmental Services Center	3
Elm City Center	1
Futures Unlimited	1
Hope School	1
Human Resources Center	1
Iroquois ARC	2
Jacksonville Area ARC	1
Latham Estates	2
MARC Center	15
Macon County Community Mental Health Board	1
Macoupin County Mental Health Center	1
Mental Health Centers of Central Illinois	2
Moultrie County Beacon	1
Progress Resources Center	1
UCP/Lincoln Land	2
Region Total	48

Appendix v (continued)

Region 4

Agency	# Clients
Citizens for the Disabled	1
Coleman Tri-County Services	1
Effingham County ARC	2
Epilepsy Association of Southwestern Illinois	1
Franklin/Williamson County Mental Health Services	1
Human Support Services	1
Illinois Center for Autism	41
Jefferson County Comprehensive Services	1
Lawrence/Crawford County Association	1
M.A.P. Training Center	1
Madison County ARC	1
Promise Center for Developmental Disabilities	4
Rehabilitation and Vocational Education (R.A.V.E.)	1
St. Clair Association Vocational Enterprises	1
St. Clair Comprehensive Mental Health Center	1
St. Clair County 708 Board	3
Washington County Vocational Workshop	1
Region Total	63

Appendix v (continued)

Region 5A

Agency	# Clients
Association House of Chicago	3
The Center for the Rehabilitation and Training of the Handicapped	15
Chicago ARC	6
Community Alternatives Unlimited	3
Gateway to Learning	5
Habilitative Systems	2
Illinois Masonic Medical Center	7
Jewish Federation	1
Lutheran Social Services	2
Misericordia Home	1
New Horizon Center for the Developmental Disabilities	4
North Center for Handicapped Children	3
Search Developmental Center	1
Victor C. Neumann Association	23
Region Total	76

Appendix v (continued)

Region 5B

Agency	# Clients
Abraham Lincoln Centre	14
Ada S. McKinley Community Services	3
Bobby E. Wright Comprehensive Community Mental Health Center	9
Easter Seal Society of Metro Chicago	33
Englewood Health Services	6
Esperanza School	10
Inter Agency, Inc.	1
Mile Square Health Center	1
N.I.A. Comprehensive Center for Developmental Disabilities	3
Wyler Children's Hospital	1
Claretian Medical Center	2
Region Total	83

Appendix v (continued)

Region 6

Agency	# Clients
Cornerstone Services	5
Easter Seal Society of Will County	6
Good Shepherd Center for Exceptional Children	5
Little Friends	6
Marklund Home	1
New Hope School	2
Park Lawn School and Activity Center	3
Ray Graham Association for the Handicapped	17
Sertoma Job Training Center	3
Southwest Community Services	2
Will County UCP	7
Region Total	57
Statewide Community Total	564

Appendix v (continued)

State Facilities

Facility	# Clients
Anna (outpatient)	4
Howe	7
Jacksonville	1
Lincoln	6
Ludeman	8
Madden (outpatient)	2
Meyer	1
Murray	3
Tinley Park	1
Waukegan	2
Waukegan (outpatient)	9
State Facility Total	44

Appendix v (continued)

Out of State Facilities

Facility	# Clients
Chileda Habilitation Institute LaCrosse, Wisconsin	3
Willowglen Academy Milwaukee, Wisconsin	5
Woodhaven Learning Center Columbia, Missouri	1
Out-of-State Total	9

Appendix vi

Illinois Agencies Providing Respite Services
FY 1987

Agency	Residential/Group Respite	In Home Respite
Abraham Lincoln Centre 3858 South Cottage Grove Chicago, Illinois 60653		X
Adams County Mental Health Center 4409 Maine Street, Box 3246 Quincy, Illinois 62305	X	X
Aid to Retarded Citizens, Springfield 2719 South 11th Springfield, Illinois 62703	X	X
Association for the Handicapped 570 West Lamm Road Freeport, Illinois 61032		X
Association for Individual Development 309 West New Indian Trail Court Aurora, Illinois 60506	X	X
ARC of Henry/Stark Counties 319-329 North Main Street Kewanee, Illinois 61443		X
Augustana Center 7464 North Sheridan Road Chicago, Illinois 60626	X	
The Center for the Rehabilitation and Training of the Handicapped 6610 North Clark Street Chicago, Illinois 60626		X
Chicago ARC 8 South Michigan Chicago, Illinois 60603		X
Children's Development Center 650 North Main Street Rockford, Illinois 61103	X	
Christian County Mental Health Association 421 West Market Street, P.O. Box 438 Taylorville, Illinois 62568	X	X

Appendix vi (continued)

Agency	Residential/Group Respite	In Home Respite
Coles County Association for the Retarded 825 18th Street, Box 487 Charleston, Illinois 61920	X	X
Community Support Services 930 Barnsdale Road LaGrange Park, Illinois 60525		X
Countryside Association for the Handicapped P.O. Box 664 Barrington, Illinois 60010	X	X
Developmental Services Center 1304 West Bradley Champaign, Illinois 61820	X	X
Easter Seal Society of Will County 257 Springfield Avenue Joliet, Illinois 60435	X	
Effingham County ARC 618 West Main Street Teutopolis, Illinois 62467	X	X
El Valor 1850 West 21st Street Chicago, Illinois 60608		X
Futures Unlimited 210 East Torrance, Box 191 Pontiac, Illinois 61764	X	X
Gateway to Learning 3911 North Monticello Avenue Chicago, Illinois 60618		X
Glenkirk ARC 3675 Commercial Avenue Northbrook, Illinois 60062	X	X
Good Shepherd Center for Exceptional Children 2220 Carroll Parkway Flossmoor, Illinois 60422		X
Habilitative Systems 415 South Kilpatrick Street Chicago, Illinois 60644		X

Appendix vi (continued)

Agency	Residential/Group Respite	In Home Respite
Hope School 50 Hazel Lane Springfield, Illinois 62703	X	
Human Resources Center 753 East Court, P.O. Box 302 Paris, Illinois 61944	X	X
Iroquois ARC Box 324, 9th & Cemetery Watseka, Illinois 60970	X	X
Jacksonville Area ARC 1201 South Main, P.O. Box 400 Jacksonville, Illinois 62651	X	X
Jayne Shover Easter Seals 799 South McLean Boulevard Elgin, Illinois 60120		X
Lawson Children's Home 1820 Lawson Drive Loves Park, Illinois 61111	X	
Little Friends 140 North Wright Naperville, Illinois 60540	X	
MARC Center 108 East Market Bloomington, Illinois 62792	X	X
Madison County ARC 400 South Main Wood River, Illinois 62095	X	X
Marklund Home 164 South Prairie Avenue, Box 10 Bloomingdale, Illinois 60108	X	
Macoupin County Mental Health Center 100½ North Side of Square Carlinville, Illinois 62626		X
Mental Health Centers of Central Illinois 710 North 8th Street Springfield, Illinois 62702	X	X

Appendix vi (continued)

Agency	Residential/Group Respite	In Home Respite
Michael Reese Hospital 434 East 26th Street Chicago, Illinois 60616	X	
Misericordia South 2916 West 47th Street Chicago, Illinois 60632	X	
Moultrie County Beacon 501 West Water Street Sullivan, Illinois 61951	X	X
McHenry County ARC 4001 Dayton Street McHenry, Illinois 60050	X	X
N.I.A. Comprehensive Center for Developmental Disabilities 7145 South Parnell Chicago, Illinois 60621		X
North Center for Handicapped Children 6423 North Bell Avenue Chicago, Illinois 60645		X
Open Door Rehabilitation Center 11 Fayette Street Sandwich, Illinois 60548	X	
Orchard Village 7660 Marmora Village Skokie, Illinois 60077		X
Peoria ARC 320 East Armstrong Peoria, Illinois 61603	X	X
Piatt County Mental Health Centers 125 West Lafayette Street Monticello, Illinois 61856	X	X
Progress Resources Center 3475 North Maple Street Decatur, Illinois 62526	X	X
Promise Center for Developmental Disabilities 2900 State Street East St. Louis, Illinois 62205		X

Appendix vi (continued)

Agency	Residential/Group Respite	In Home Respite
Ray Graham Association for the Handicapped 420 West Madison Elmhurst, Illinois 60126	X	X
Sertoma Job Training Center 4343 West 123rd Street Alsip, Illinois 60658	X	
Shelby County Mental Health Center 1810 West South 3rd Street Shelbyville, Illinois 62565		X
St. Clair Association Vocational Enterprises R.R. #1, P.O. Box 71R Belleville, Illinois 62221	X	
Sunshine Activity Center 4842 West Diversey Chicago, Illinois 60639	X	
Tazewell County Resource Center 1605 Florence Pekin, Illinois 61554		X
UCP of Will County 311 South Reed Street Joliet, Illinois 60436		X
Vermillion Mental Health Center 605 North Logan Danville, Illinois 61832		X
Warren Achievement Center 1314 South Main Street, P.O. Box 366 Monmouth, Illinois 61462	X	X
Will County Sheltered Workshop 611 East Cass Street Joliet, Illinois 60432	X	

Appendix vii

DMHDD Clients With Autism

By Type of Day Service Received

Based on ICIS Report 8/31/86

Type of Day Program	Number of Clients
Regular Work	51
Developmental Training I - Adults	90
Developmental Training - Children 0-21	161
Public School	52
Developmental Training II - Adults	53
Other	17
Blank/Miscoded	193
Total	617

Appendix viii

Summary

AUTISM SERVICE SYSTEM

Huntington, West Virginia

The Autism Service System, founded in 1979 by Ruth Sullivan, has as its motto: "If it's an autism job, we can do it." This organization functions primarily as a national information and referral source, concentrating on providing training in autism for public school districts, state developmental disabilities councils, and state facilities. It also staffs a national autism hotline which provides advocacy services especially for parents of individuals with autism.

In addition, Autism Service System operates the Katrina Project, a residential program in which an individual with autism lives in an apartment with a family. Support staff are available to assist the family as needed.

The organization provides summer camp services for 15-19 individuals with autism and has recently started a supported employment program serving two people.

Appendix viii (continued)

Summary

AUTISM SERVICES ASSOCIATION

Weston, Massachusetts

The Autism Services Association is a private not-for-profit organization founded in 1963 to advocate for persons with autism. The basic philosophy is to support people in their local communities no matter what their level of ability and to promote their participation in the community while relying solely on the use of positive behavioral change techniques.

A unique component of their program is the use of regional resource teams, each including four specialists in autism, to provide crisis intervention for persons who are not receiving services or are receiving inappropriate services. The teams conduct staff training as well and provide case management services for 85 individuals.

The Association serves twenty autistic individuals in a supported employment program. A recently started Integration Resource Project provides training to public school districts in the integration of severely handicapped and autistic children into the regular classroom.

Appendix viii (continued)

Summary

CHESTOR HOUSE

Boulder, Colorado

Chestor House was founded in 1982 by a group comprised of parents of adults and children with autism. These children and adults with autism resided in both institutional and noninstitutional settings at that time. Chestor House operates a residence for eight adults with autism. Admission is targeted to individuals who are leaving institutional settings or who are at risk of placement in an institutional environment. The treatment approach does not rely on the use of psychotropics for behavior control; positive intervention and behavior modification techniques are instead used for dealing with challenging behaviors.

Emphasis is also placed on integration with the community and adult work programs which afford greater opportunity for development of independent living skills. Of the eight residents currently in the home, six are participating in supported employment and two are receiving day services through a Developmental Disabilities Board program.

Appendix viii (continued)

Summary
COMMUNITY SERVICES FOR AUTISTIC ADULTS AND CHILDREN (CSAAC)

Rockville, Maryland

Community Services for Autistic Adults and Children (CSAAC) is a private, nonprofit agency dedicated to education, training and welfare of persons disabled by autism. It was developed by parents and professionals of the Maryland Society for Autistic Adults and Children in 1979 in response to the lack of services for adolescents and adults with autism in Maryland. Without these services 95% of this population was eventually institutionalized. In 1982 CSAAC was formed as a separate provider agency. In March, 1984, CSAAC was granted two-year accreditation by the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons (ACMRDD). It thus became the first ACMRDD-accredited program designed specifically to serve persons with autism.

The CSAAC Board of Directors and staff believe all people with autism can be served in the community. In September, 1984, CSAAC was recognized by the Office of Special Education and Rehabilitation Services (OSERS) as a model program, and was granted Federal funds to refine and disseminate CSAAC methods.

This program admits children and adults who are disabled by autism and unable to currently function in a less restrictive environment. Services provided include:

- Adult Residential - residential services are offered to adults with autism as an alternative to institutionalization. Residences range from apartments and townhouses to single family dwellings and are located throughout Montgomery County. Counselors live with residents on a rotating basis and are responsible for teaching skills as specified in a plan of care. A wide range of positive behavior management techniques are used to modify disruptive or inappropriate behaviors.

- Adult Vocational - Day programs offer a wide range of vocational options to adults with autism regardless of their functioning level. Services include evaluation, care planning, personal adjustment, habilitation, travel training, work training, and on the job training. Clients receive training in work training sites and assistance from CSAAC counselors.

- Adolescent Services - The Community School of Maryland serves severely and profoundly handicapped adolescents with autism. Education, vocational training, and related services are provided in a 24-hour, 12 month program. A minimum staff - pupil ratio of 1:2 is maintained at all times.

Summary

COUNCIL OF ORGANIZATIONS AND SCHOOLS FOR AUTISTIC CHILDREN AND ADULTS, INC. (COSAC)

Lawrenceville, New Jersey

The New Jersey Council of Organizations and Schools for Autistic Children and Adults (COSAC) is incorporated to assist families, individuals, and agencies concerned with the welfare and education of children and adults with autism. COSAC is dedicated to promoting growth in services and providing a forum to exchange and develop information to benefit children and adults with autism. All state approved programs in New Jersey serving individuals with autism are eligible for membership in COSAC. COSAC finds it desirable for member agencies to develop policies regarding the design, implementation and evaluation of programs and services and to foster a cooperative network with families and professionals. COSAC is concerned with encouraging the use of best clinical practice in service delivery. Due to variations in the educational treatment of individuals with autism endorsement or approval of the policies of individual members cannot be provided.

The Autism Helpline and Information Clearinghouse was established as part of COSAC's public information effort. This helpline enables people to obtain information, request short term emergency care, or to make arrangements for a speaker through the Speaker's Bureau. Emergency situations may include absence of the primary caregiver due to illness or death or temporary change in work schedule. Short term care ranges from 4 to 48 hours.

APPROPRIATE LIVING FOR AUTISTIC

Wyckoff, New Jersey

An example of a member of this organization is Appropriate Living for Autistic (ALFA) which operates a respite program for persons with autism. A survey conducted by this agency in 1985 found respite to be a key need for families with autistic relatives. The services identified as most helpful by families were home training and relief time for caregivers. Thirty-five clients, age 2 to 30, are served by the program. The family is involved in scheduling respite services and must be present during the first six visits to develop a treatment plan. Parent training and qualified staff are key components of this program.

Appendix viii (continued)

Summary

DIVISION TEACCH

Chapel Hill, North Carolina

The Division for the Treatment and Education of Autistic and related Communication handicapped CHildren (TEACCH) is a statewide, comprehensive, community-based program including direct service, consultation, research, and professional training. It is dedicated to improving understanding and services for children and adults with autism and related communication handicaps and is located in the Department of Psychiatry, School of Medicine, at The University of North Carolina at Chapel Hill.

The program, administered through five regional centers in North Carolina, is affiliated with over 60 public school classrooms, 10 group homes, and local parent groups concerned with this population. Close working relationships with other public and private agencies, professional and parent organizations, such as the North Carolina Society for Autistic Adults and Children, assure well-coordinated services throughout the state.

The primary aim of TEACCH is to assist in preparing individuals with autism to live or work more effectively in the community and to prevent unnecessary institutionalization. Division TEACCH provides the following major services: diagnostic evaluation, individualized treatment, parent and teacher training, and consultation to classrooms, school systems, parent groups, and other agencies involved in the care of autistic persons. Other special services are model program development and crisis intervention.

TEACCH, in conjunction with the North Carolina Department of Public Instruction, sponsors workshops focusing on a variety of topics related to the education of autistic children, including classroom organization and techniques, behavior management, language, working with families, assessment and prevocational skills. Training activities place special emphasis on the need to individualize instruction, involve parents in treatment, and integrate the child's school and home learning environments. An intensive in-service training program is also offered to TEACCH staff, parents, and children.

Summary

JAY NOLAN CENTER

Los Angeles County, California

The Jay Nolan Center is one of the largest programs in the country serving people with autism. The Center emphasizes normalization, social integration, positive programming, alternative communication systems, and use of non-aversive techniques. This program was initiated in 1975 and operates as a nonprofit corporation.

The following programs are offered by the Jay Nolan Center:

- Residential Services - Homes and apartments are located in Santa Clarita and San Fernando Valleys. Each home is staffed with individuals trained in communication and behavior problems.

- Occupational Training Centers - Calypso and Chrysalis are programs designed to provide a structured approach toward developing and maintaining positive behaviors. Occupational skill development is geared toward the individual's interests. The Chrysalis program provides less intensive staffing and is intended to transition participants to the least restrictive programming and perhaps competitive employment.

- Sitter/Respite Program - This is a comprehensive in-home respite service, offering short term care to persons in need. Staff are required to complete 20 hours of instruction and eight hours of field service. The intent of respite is to stabilize the family situation and reduce the possibility of alternative placement.

- Saturday Recreation - This program provides age appropriate socialization and leisure time skills for nearly 200 children in the Los Angeles area. Activities are supervised by trained staff and may range from language and communication skill development to sports training. The Saturday program also mainstreams individuals into community activities and provides parents a respite opportunity.

- Extended Year Program - This program bridges the gap in public school schedules during holiday and vacation breaks. Structured training is provided in recreation, language, and communication activities.

Summary

RESIDENTIAL CARE FOR THE DEVELOPMENTALLY DISABLED, INC.

Oshkosh, Wisconsin

This agency provides residential support for 116 individuals who are developmentally disabled and in need of residential care. An example of the residential program for individuals with autism is the Nebraska Street Group Home, a 6-bed residential facility. Flexibility in funding and staffing have made it possible for the complex needs of these people to be addressed in a community setting. This home was initially started in 1975 as a child group home, but changed its licensing to adult as the residents attained the age of 18.

The goal of the group home is to provide a home-like alternative to institutionalization. Additional goals are to promote skill development, to facilitate independence and self-reliance, and to promote mainstreaming into the community. The program serves severely disabled persons who in the past were considered unlikely placements for community settings. The program provides specialized services through trained staff, but also promotes the use of general community resources.

Admission to the program is through the Winnebago County Unified Board, which utilizes staff and consultants to evaluate physical, social, behavioral and emotional factors of the applicant. After admission, the development of a program plan is a cooperative effort among program staff, parents and guardians, the recipient of services where possible, and the county unified board staff.

Appendix ix

CRA/HIP Rate Methodology

I. General Description - CRA/HIP Programs

A. Target Population

These programs are for those developmentally disabled individuals unable to live independently but capable of community living if provided with an appropriate level of supervision and support services, and without great medical needs. CRA programs may serve only adults, while HIP programs may serve adults or children. HIP programs may serve 1 or 2 clients; CRA's may be licensed for eight or fewer.

B. Primary Mechanism

CRA/HIP rates are cost-based up to statewide average ceilings for three separate components: Program, Support, and Ownership/Occupancy (which may contain a vehicle allowance). Rates are updated annually based on the facility's last audited fiscal year's costs, updated for inflation. Cost data submitted by providers are subject to certain adjustments for costs which are non-allowable by DMHDD.

C. Summary of Methodology

Costs are separated into three basic categories: Program, Support, and Ownership/Occupancy. There is also a provision for a Vehicle Allowance to cover the cost of leasing or purchasing vehicles.

Program: Providers will receive their allowable program costs, up to a maximum of $43.15, adjusted by HSA. Administrative costs are part of the program component, and are limited to 20% of all other allowable costs.

Support: Providers will receive their allowable support costs, up to a maximum of $13.94, adjusted by HSA. If their costs are less than the maximum, they will receive an additional amount of 1/2 the difference between their costs and $13.94.

Ownership/Occupancy: Providers will receive their allowable ownership/occupancy costs, up to a maximum of $8.20, adjusted by HSA. If their costs are less than the maximum, they will receive an additional amount of 1/2 the difference between their costs and $8.20.

Vehicle Allowance: The costs of either depreciation/interest or lease of a vehicle, if any, are subtracted from the ownership/occupancy component and treated separately. Providers may receive up to a maximum of $1.83, not adjusted by HSA, only if a vehicle has been acquired for that specific program.

II. Rate Determination

A. Components

Program: Program costs are defined as the sum of lines 11, 25, and 31 from Schedule IV of the ISFR.

Support: Support costs are defined as the sum of lines 17 and 37 from Schedule IV of the ISFR.

Ownership/Occupancy: Ownership/occupancy costs are defined as the sum of lines 43, 48, and 52 from Schedule IV of the ISFR.

Vehicle: Vehicle costs may be all or a portion of lines 39, 45 and 51 from Schedule IV of the ISFR. It is necessary to check Schedule I and their supplemental schedules to determine which of these costs are vehicle-related.

NOTE: For HUD-funded facilities, the methodology is applied only to the costs identified as those to be DMHDD-funded, and no "1/2 the difference" allowances are made.

B. Divisor

The divisor is determined by the actual days of utilization, up to a maximum of 98% of possible days, with 90% of possible days being the minimum divisor used.

C. Cost Containment

Fringe benefits are limited to 20% of salaries. Administration is limited to 20% of all other reimbursable costs. Component ceilings are established by finding the 70th percentile of costs for all programs reported, for each component. These ceilings are then regionally adjusted, using HSA adjustors.

D. For FY 1986 rate increases were limited to 5% over the last rate for each program. This corresponds with the 5% COL increase which was included in DMHDD's budget for rate increases.

III. There are currently 89 CRA's, serving 600 clients, with the weighted average rate being $57.81 (as of 3/31/86). For HIP programs, the weighted average rate is $56.28 (as of 3/31/86) for 100 programs, serving 190 clients.

JANUARY 1987

A REPORT ON THE SERVICE NEEDS OF PERSONS WITH AUTISM

EXECUTIVE SUMMARY

REPORT TO THE ILLINOIS GENERAL ASSEMBLY
IN RESPONSE TO
PUBLIC ACT 84-1291

Illinois Department of Mental Health and Developmental Disabilities

INTRODUCTION

The purpose of the report summarized herein is to review the service needs of persons with autism, to explore service models, and to detail a plan of action to address appropriate services for this population.

This report responds to the requirements of Public Act 84-1291 (H.B. 2816), which requires the submission of a report to the General Assembly by January 1, 1987.

Definition

For purposes of this report, the Department of Mental Health and Developmental Disabilities will adopt both the definitions contained in the Mental Health and Developmental Disabilities Code as well as the more descriptive definition of P.A. 84-1291.

Specifically, the Mental Health and Developmental Disabilities Code defines developmental disabilities as:

> .. disability which is attributable to: (a) mental retardation, cerebral palsy, epilepsy, or autism; or to (b) any other condition which results in impairment similar to that caused by mental retardation and which requires services similar to those required by mentally retarded persons. Such disability must originate before the age of 18 years, be expected to continue indefinitely, and constitute a substantial handicap. (Chapter 91 ½, Section 1-106).

P.A. 84-1291 affirms that autism is a severely incapacitating lifelong developmental disability and further describes:

a. May be manifested before a person is 30 months of age.

b. May be caused by physical disorders of the brain, and;

c. Is characterized by uneven intellectual development and a combination of disturbances in the rates and sequences of cognitive, affective, psychomotor, language, and speech development. This syndrome is further evidenced by abnormal response to sensory stimuli, problems in developing social relationships, and ritualistic and compulsive behavior. (Chapter 91 ½, Section 100-56).

Consistent with the above definitions, the National Society for Children and Adults with Autism (NSAC) defines autism as:

> .. a disability that severely impairs the way sensory input is processed, causing problems in communication, social behavior and in learning. It typically appears during the first thirty months of life. Symptoms of autism occur in approximately 15 out of every 10,000 births, and are four times more common in males than females. It has been found throughout

the world in families of all racial, ethnic, and social backgrounds. No factors in the psychological environment of a child have been shown to cause autism. There is strong evidence of neurological and biochemical implications. (NSAC, Autism Fact Sheet, No. 83-1877).

Autism is thus established as a severe disability which originates early in life and can be expected to continue indefinitely. It is important to understand, however, that the characteristics of autism may vary significantly among persons with autism, depending upon the degree of cognitive, behavior, and communication disorder and the manner in which these disorders are manifested. It should also be emphasized that many in the field believe that autism is first and foremost a communications disorder which dictates the type and approach to service delivery. The recognition of these variations in the severity of the disorder is most important to understand the variety of treatment types and service needs.

Characteristics of the Syndrome

Common characteristics of autism are:

- Severe impairment of speech or lack of speech
  - echolalia, jargon, and word order confusion
  - poor volume control and inappropriate inflection
  - inability to understand and/or process verbal or nonverbal communication
  - pronomial reversals
  - rote-like, memorized phrases and expressions

- Impairment or complete lack of appropriate relatedness or interaction with single children, parents, adults, and objects
  - avoidance of eye contact
  - abnormal degree of detachment or non-affection
  - abnormal degree of attachment to objects
  - grossly inappropriate behavior reactions (e.g., tantrums, inappropriate laughter)

- Extreme distress due to minor non-discernible changes in the environment (structure or time)

- Lack of intellectual development or retardation in language and cognition, although sometimes accompanied by normal or superior abilities in other areas

- Repetitive, peculiar, and inappropriate use of toys and objects
  - bizarre mannerisms
  - self-stimulation (e.g., hand flicking, humming)
  - repetitive body motions (e.g., rocking, spinning)
  - ritualisms and/or repetitive behavior

- Unusual reactions to perceptual stimuli, such as seeming not to hear certain sounds and over-reacting to others, holding hands over ears, "looking through" objects, and poor eye contact

- Inability to perform certain gross and/or fine motor activities (e.g., walking with a peculiar gait, limpness in fingers, inability to hold a pencil appropriately)

- Onset of disorders at birth or apparently normal early development followed by failure to maintain normal functioning, especially in critical cognitive and communicative areas

- Tendency to fixate on the extreme polarities of behavior
  - hyperactivity or passivity
  - apparent insensitivity to pain or hypersensitivity to tactile stimulation

- Self-injurious, destructive and aggressive behavior.

(State of Delaware General Guidelines for the Development of Programs of Special Education and Related Services for Children and Youth with Autism).

SERVICE NEEDS FOR AUTISM

Based upon the review of client characteristics and model programs, the following list of service needs for the autistic population can be identified.

Family Programs and In-Home Behavior Management

In conjunction with day programs there must be a home-based program that helps families handle problems arising in the home environment and that provides consistency in behavioral programming for the autistic individual. Parents and siblings benefit from training in behavior management, language and communication, and medical management. Families can receive support through counseling, networking with other families, and receiving help with planning for the autistic individual's future. Most importantly, in-home and out-of-home respite services are critical in maintaining individuals with autism in the home.

Diagnostic Assessment

A full interdisciplinary diagnostic assessment is a necessity. Since the onset of autism is typically before 30 months of age, immediate and accurate diagnosis is essential when problems are suspected, so that appropriate early intervention can begin. Assessment should include delineation of assets and deficits, behavioral analysis, language evaluation, and medical and dental screening. Periodic reassessments are required by changing problems and circumstances. For example, during transition from school programs to adult programs some families have noted instances where higher functioning autistic individuals were misdiagnosed as mentally ill rather than autistic. They also report hesitance to diagnose and label adults as autistic as it may exclude them from generic adult developmental disability services.

Case Coordination

The ability to identify service needs consistent with identified client problems, to link people to available resources, and to monitor the provision of services are key functions of case coordination units. This service must be available for persons with autism in order to ensure appropriate service delivery. Specialized training on autism needs to be given to case coordinators to increase their effectiveness with this population.

Educational/Vocational/Employment Programs

Classrooms and vocational settings specifically designed for autistic individuals may be necessary. While segregated programs are not necessarily preferable, they have the advantage of having the expertise and specialized programming required to teach these individuals. Programs designed more generally for developmentally disabled people have often excluded the more severely disturbed autistic individuals from their programs. In terms of integration in non-handicapped settings, DeMyer (1982) estimates that only 10% of autistic children can be accommodated satisfactorily in a classroom with normal age mates, even after intensive therapy. However, the Louisville School

for Autistic Children in Kentucky has been able to successfully integrate all its students with autism into the regular public school system. Community integration is not an all or nothing issue. For instance, children can be mainstreamed in some classes or recreational programs and not others.

Work opportunities such as supported employment and supported work need to be considered for persons with autism. In some cases, individuals graduating from public school programs may be capable of directly entering a work program. However, the majority of persons with autism could not function independently on a job without ongoing supervision. Yet there is no reason to keep them separated from the general work force as long as trained supervisors ("job coaches") are there to manage behaviors. Other day programming options which are used include adult day programs, developmental training, sheltered workshops, and work activity.

Residential Programs

In most circumstances it is preferable for younger autistic children to live with their families, but in some circumstances due to family stresses and extreme caretaking demands, residential placement may be needed. As autistic children get older, this need for residential care increases.

For adults, institutional care, which may be inappropriate, is often the only option available. Estimates by Dr. Ruth Sullivan are that most autistic adults reside in institutional settings. The physical size of adults and their behavioral difficulties may create significant management problems for their families. This is why a focus on more resources for the children is needed so that their behaviors do not escalate as they become older. Also, as parents age and families experience illness, deaths, and divorce, they may be less able to care adequately for the autistic adult. For those individuals requiring placement outside the natural home, it is clear that integrated community living in small group homes is the most appropriate option.

Public Education/Awareness

Community acceptance is a major problem for individuals with autism, particularly due to their severe behaviors (e.g., aggressive, self-abusive). These behaviors often result in their exclusion from both generic and developmental disability community programs and services. If persons with autism are going to be physically and socially integrated and not institutionalized, then public education is needed. This can be done in conjunction with other public information programs more generally about developmental disabilities, by adding a component on autism. Public relations material from advocacy associations can also help foster community acceptance of these individuals.

Professional/Paraprofessional Training

Specialized professional training regarding autism is needed because very few professionals, in <u>any</u> discipline, have the knowledge and technology to effectively serve persons with autism. Although autism is a severe disorder,

it is of low frequency, and hence is often neglected in university training programs. Many times, the behaviors seen in these individuals are only partially attributable to the condition. Poor behavioral programming due to insufficient expertise in professionals may exacerbate these behavioral problems. Professional/paraprofessional training efforts need to include university-sponsored staff in-service training and ongoing networking between professionals in the field.

RECOMMENDATIONS

In order to enhance the quality of care provided to persons with autism and to ensure that appropriate services are developed, the following actions are recommended.

1. **Ensure proper identification of autism by increasing the knowledge of autism among parents and professionals and increasing general public awareness of the syndrome.**

Implementation Plan

- Develop a resource manual that will increase public awareness as well as parental and professional awareness of the characteristics of autism and available services within the state. In New Jersey, the Developmental Disabilities Council developed a pamphlet which contained a list of resources throughout the state for evaluation and early diagnosis of disability. A similar resource document should be developed in Illinois.

- The distribution of this resource document should include physicians, health care professionals, psychologists, service providers, case coordinators, and parents.

- The state should designate existing multipurpose and interdisciplinary facilities in Illinois to develop diagnosis and assessment capability for autism. These centers should be available for conducting comprehensive evaluations of persons with severe behavior or communication disorders and for consultation by case coordinators. The low incidence of autism limits the feasibility of establishing new diagnostic programs for the sole purpose of autism.

- Training should be provided to diagnosticians in existing facilities and case coordination agencies to enhance their knowledge and understanding of autism.

2. **Assure the availability of early intervention services for children with autism and their parents so that intervention can occur at the earliest possible time.**

Implementation Plan

- In line with the approach taken by model programs, early intervention for children with autism should occur whenever feasible in programs which are not exclusively for autism. Often autism is not identified at this early age, but options for parent involvement in training and infant stimulation must be provided.

- Programs should emphasize an interdisciplinary and individualized approach in carrying out training to enable children with a variety of disabilities to be served.

- In carrying out the above objectives, it is especially important that the staff in early intervention programs receive appropriate training in dealing with characteristics of autism (see Recommendation #3).

3. **Establish an ongoing training system for agencies and parents to provide expertise in the area of autism.**

Implementation Plan

- Resources should be provided to assure in-service training for professional and direct care staff who work with severely disabled and autistic children and adults to ensure their understanding of the care and teaching techniques for persons with autism. This training should be provided to all new employees and periodically thereafter. Training should be available in both state facilities and community agencies. High quality in-service training programs currently operated by Illinois community agencies should be considered for dissemination to other facilities. In addition, training models operational in other states should be considered for application in Illinois. Two such programs are the National Personnel Training of Ann Donnelan, Lou Brown, and Gary LaVigna, and the TEACCH program directed by Eric Schopler. It is further recommended that a training complement be established within the state to provide ongoing and on-site training. A "train the trainer" approach is highly desirable for use due to the ability to train larger number of persons from a small initial training complement.

- Training should be made available for parents and siblings as well to encourage their active involvement in the care of their children and to recognize their value as in-home therapists. In fact, many experts believe parent and family training may be the key element in programming for autistic children, due to the extent of time spent with the child. Again, the TEACCH model trains parents to work with their children in managing behavior problems and improving language, social, and learning skills.

4. **Enhance family support mechanisms to enable persons with autism to remain in the home environment.**

Implementation Plan

In a needs survey conducted by the Governor's Planning Council on Developmental Disabilities, respite care services were identified as the most urgently needed family support service for persons with developmental disabilities. It is clear that the availability of respite care contributes to the stability of families who keep their children at home. Specific implementation tasks are:

- A special model of respite care is needed for families with autistic children that allows for more intensive support and follows the concepts of respite provided in model programs. This includes trained respite sitters, day respite for weekends, and after school or after work programs. Further, a consistent standard is needed in the number of hours

allotted for respite care. As an example, the Appropriate Living for Autistic (ALFA) program, a member of the COSAC in New Jersey, develops a respite schedule in advance which typically includes 25 to 40 hours per month of in-home care. In some cases of high need, maximum hours must be determined on a case by case basis.

- Particular emphasis must be placed on the availability of respite care for adults with autism as many areas of the state and some provider agencies do not offer such care. Emergency respite or temporary residences must also be available to families of children with autism thus avoiding a permanent placement of the child away from the home, but allowing an urgent need to be readily addressed.

- Respite workers should receive specialized training in the care of persons with autism.

5. **Ensure an adequate transition from public school programs to adult work and day programs for persons with autism and provide day services to adults currently unserved or not appropriately served.**

Implementation Plan

This report does not address in detail the transition and public school program issues for individuals with autism. These will be addressed in the DMHDD/ISBE study currently underway. However, the significance of the issue facing parents with adolescents and teenagers who have autism does necessitate its inclusion in this report.

- It is generally recommended that transition planning begin in early adolescence to facilitate access to adult services. It is further recommended that transition planning for persons with autism emphasize participation in work or supported employment programs to the degree possible.

- The availability of adult work and day programs should be targeted to geographic areas demonstrating greatest current need and ability to document clients who are now or within the next three years will be graduating from public school programs. The work models developed, both in Illinois and in other states, should be considered for replication.

6. **Ensure that individuals with autism are afforded opportunities to reside in alternative settings which maximize potential for growth and offer a least restrictive and age appropriate setting.**

Implementation Plan

- It is recommended that residential settings for persons with autism be increased. These settings must be small (no larger than six) and funding methodologies must be flexible enough to allow for more intensive staff ratios on an ongoing basis. Special behavior programming should also be available on a case-by-case basis to deal with the short-term and intermittent needs of persons with severe behavior problems.

- DMHDD should continue to require that group homes for persons with autism be licensed as Community Residential Alternatives (CRAs), but that implementation of programming be individualized and adapted to more intensive client needs. Residential programs should promote normal daily living and make use of community resources.

- Autism should be targeted in request for proposal development to assure expansion of community residential group homes within overall Department growth of residential settings.

- Group home staff should receive special training in skills needed to care for persons with autism. This should include both in-service and pre-service training.

Fiscal Considerations

To carry out many of the above recommendations, increased revenues will be needed to expand the DMHDD budget. The Department recognizes that the dollar amounts will be contingent upon the limits in state revenues. A commitment is given, however, to target a portion of FY 1988 budget increases, exclusive of cost of living, to enhance services to persons with autism.

It is further recognized that the above strategies will call for multi-year implementation. The recommendations thus assume that future year funding will be needed to continue to address the needs of the current clients and those "aging out" or graduating from public school programs.

Finally, the request for resources to support family care and enhance employment and community integration opportunities for persons with autism must be contrasted with the cost of the alternatives: state facility or nursing home care for the majority of the population. If even a portion of the estimate of 90% institutionalization for autistic adults were to occur in Illinois, the long run costs would be staggering. State facility per annums currently average over $40,000 per developmentally disabled resident. In contrast, the average cost per person of the Medicaid waiver initiative, a program which offers a comprehensive package of residential, day program and community support services, is estimated to be $27,000 in this fiscal year. Thus, the most expensive community package still falls far short of the typical state facility cost.

The options recommended herein are even less costly than the Medicaid community initiative. If only respite care, parent training, or day programs are needed, it is likely that costs would range from $3,000 to $18,000 per client. The implementation of training also offers a relatively low cost option which can help a greater number of individuals.

CONCLUSION

The philosophy of autism programs is to assure dignity and community presence at the maximum level of independence for individuals with autism through services which incorporate the following dimensions:

- Early identification of the syndrome;
- Support services to schools and human service agencies;
- Assistance in securing and retaining optimal employment or work opportunities;
- Facilitation of placement in the least restrictive community setting;
- A network of resources for professionals and families;
- Anticipated support of a lifelong duration.

The Department's report on the service needs of persons with autism thus calls for stronger support of families in their efforts to maintain autistic children and adults in the home and more individualized consideration of service options. The report emphasizes the need for flexibility in the system to deal with the unique needs of the autistic population. The report additionally calls for recognition of the need for adult residential care and corresponding changes in funding methodologies. The implementation of these recommendations will facilitate the opportunity for persons with autism to learn, grow and work in a supportive environment.

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